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ABSTRACT

This literature review focuses on the characteristics of children who are technology supported and on the experiences of families who have undertaken home care of such children. It presents information on: (1) medical, cognitive, physical, and socio-emotional characteristics of the children; (2) experiences within the family; and (3) family interactions with agencies and persons outside of the family. Definitions of "technology support" and "chronic illness" are provided. The nature and purposes of technology support (i.e., ventilators, intravenous nutrition, and long-term intravenous drug therapy) are discussed, as are the organicity/etiology of conditions creating technology dependence and prevalence estimates. Among other topics covered are demographics (age, gender, and ethnicities), duration of ventilator-dependence, prognosis, hospitalization, demographics of families, socio-emotional characteristics of families, parent-child relations, child rearing, spousal relationships, sibling relationships, extended family relationships, family interactions with medical/human services, model home care programs, home nursing care, a Model Day Care Facility for Children who are Technology-Supported, barriers to home care, family interactions with the educational system, school absenteeism, barriers to integration, family experiences with insurance/financing, family relationships with the community, and implications for research. Contains 88 references. (DB)

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A Literature Review of Topics Concerning Children Who Are Technology-Supported and Their Families

Sandra Condry, Ph.D

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A Literature Review of Topics Concerning Children Who are Technology-Supported and Their Families

Sandra Condry, Ph.D.

1989

Beach Center on
Families and Disability

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Preface

The Beach Center on Families and Disability, a rehabilitation research and training center at The University of Kansas, is funded by the National Institute of Disability and Rehabilitation Research, United States Department of Education, and the University to conduct research on families with members who have disabilities. A major focus of the Center's research is the families of children who are supported by technology.

This literature review and the annotated bibliography that accompanies it were developed by the Center in order to bring into one document the present body of knowledge about these children and their families.

Sandra Condry, a research associate at the Center during 1988-89, is the author of this literature review and the annotated bibliography. She was assisted in a variety of ways by several staff of the Center, particularly Patricia A. Barber, Robert Hoyt, Harriet Shaffer, Douglas Murphy, and H. Rutherford Turnbull, III, Co-Director.

The Center is continuing to work in the area of technology support. In particular, it is conducting research on the decision-making process and the criteria by which schools and family members decide to place children with technology supports into regular or special education programs. This research is being directed by Dr. Barber, Dr. Murphy, and Mr. Turnbull. A copy of the abstract of this research is available from Mr. Turnbull.

The Beach Center welcomes any comments by readers of this literature review, and hopes that it will be useful to them.

This literature review is available for purchase from the Center. Please direct your inquiries for purchase to Harriet Shaffer, Assistant Director, Beach Center on Families and Disability, 4138 Haworth Hall, Lawrence, KS 66045, (913) 864-7600.

I. BACKGROUND

Purposes of Review

This review has three primary purposes: (1) to describe what is known about children who are technology-supported and about their families; (2) to identify barriers to the full integration of these children and their families into our society; and (3) to point out those areas where too little is known.

Focus of Review

This review focuses on characteristics of children who are technology-supported and on experiences of families who have undertaken home care of such children. It presents information on (1) medical, cognitive, physical, and socio-emotional characteristics of the children, (2) experiences within the family, and (3) family interactions with agencies and persons outside of the family.

Definitions

Definition of technology-support

A child who is technology-supported is a person under 21 years of age who has a chronic disability, requires routine use of a medical device to compensate for the loss of a life-sustaining body function, and requires daily ongoing care or monitoring by trained personnel (U.S. Department of Health and Human Services, 1988; U.S. Congress, Office of Technology Assessment, 1987a). Much of the literature refers to these children as technology-dependent. Children who are technology-supported belong to a larger group, that of children with chronic illnesses.

This definition includes children who receive ventilator assistance, parenteral (not through the digestive system) nutrition, and long-term intravenous drug therapy.

A child who is ventilator-assisted is one who requires for at least part of every day the use of a mechanical ventilator or respirator to assist in breathing.

A child who receives parenteral nutrition is one whose small intestine (enteral system) cannot absorb needed nutrients, so a total nutrient solution is infused directly into the circulatory system by way of a large vein (intravenously).

A child who receives long-term intravenous drug therapy is one who is given injections or slow infusions of chemotherapeutic drugs periodically over several months or years.

Definition of chronic illness

A child with chronic illness is one who "has a condition that interferes with daily functioning for more than three months in a year, causes hospitalization of more than one month in a year, or (at time of diagnosis) is likely to do either of these" (Hobbs, Perrin, & Ireys, p. 2, 1985).

Sources and limitations of data

Sources

Currently, the most extensive attempt to document the characteristics of children with technology-support and their families is confined to children who are ventilator-assisted (Aday, Aitken, & Wegener, 1988). This study evaluated three state-wide federally-funded projects whose goals were to develop a regionalized system of care and a model for home care of children who are ventilator-assisted. The evaluation gathered demographic data on 69% of the identified children and their families in the three states, as well as retrospective and current experiential data on 50% (N = 141) of them.

These children have been of interest to the medical research community for a longer period than to the social sciences and human services research groups. In general, the medical studies tend to focus on the etiologies, technological interventions, and prognoses for these children. Less attention is paid to other characteristics of the children and their families.

An example of relevant research coming from the medical world is a retrospective report by the health care professionals of 54 nonpoliomyelitis children discharged from the Institute for Rehabilitation and Research or Texas Children's Hospital in Houston who used either a positive or negative pressure ventilator at home between 1962 and 1983 (Frates, Splaingard, Smith, & Harrison, 1985).

Limitations of data

Small sample size is a limitation of many of the reports. For instance, longitudinal studies of children dependent on total parenteral nutrition have data on 9-12 children (the series of UCLA studies-- Cannon, Byrne, Ament, Gates, O'Connor, & Fonkalsrud, 1980; O'Connor, Ralston, & Ament, 1988; Ralston, O'Connor, Ament, Berquist, & Parmelee, 1984). Likewise, P. Walker (1988b) provided qualitative data on five families caring for their children who are ventilator-dependent, while Burr, Guyer, Todres, Abrahams, & Chiodo (1983) had data on six families with children who were ventilator-assisted. Tejani, Mahadevan, Dobias, Nangia, & Varma (1979) provide psychological and physical followup data on 34 children who received temporary total parenteral nutrition during the neonatal period.

Another, important constraint is the highly selective and biased nature of the sample of the families of children who are technology-supported to which we have access. Most of these data were collected from families who, once contacted, agreed to be interviewed. This self-selection factor is widely recognized as a limitation, although the effects it has on the data are rarely specifiable.

Moreover, these families were often involved with a program or physician or some other gate-keeper who allowed or did not allow access to the larger set of eligible families. One result of the gatekeeper issue is that almost all of the research projects reported here were confined to families who had brought home their child who was technology-supported. Families who for financial, emotional, or situational reasons did not pursue home care or who were denied the opportunity for home care, were not interviewed. (See Thomas, 1987, for a fuller discussion of these issues.)

Finally, the information presented here is usually derived from a nonrandom sample. Some data are from small circumscribed populations of children who are technology-supported. These are the experimental followup studies of technological intervention in infants or young children. In these studies the subject selection procedures were specified. Depending on the purposes to which the data are to be put, the biasing characteristics of the samples can be critical or largely irrelevant.
Generalizations must be made carefully.

Nature and Purposes of Technology Support

Ventilators

Mechanical ventilation is necessary for persons with neuromuscular diseases or conditions which prevent the lungs from receiving or exchanging adequate air, such as respiratory paralysis or alveolar hypoventilation or distributive hypoxia.

In alveolar hypoventilation, gas exchange with the blood is inadequate for removal of carbon dioxide, and not enough oxygen is delivered into the pulmonary system.

In distributive hypoxia, there is interference with the intrapulmonary distribution of the inspired air and large amounts of carbon dioxide are removed from the blood causing inadeqauate oxygenation of the blood (Miller & Keane, 1983).

Respiratory paralysis or neuromuscular paralysis results from damage to parts of the the nervous system. This can be central paralysis. In children this is often the result of failure of the brain to develop properly in intrauterine life or of injuries to the brain. It also may be due to damage to the spinal cord due to direct injuries, tumors, or infectious diseases. Ondine's curse is an example. Or there can be peripheral paralysis, which until recently was most frequently caused by poliomyelitis (Miller & Keane, 1983). Tuberculosis and kyphoscoliosis (curvature of the spine including hunchback) can also cause restrictive lung disease (Fischer & Prentice, 1982).

Ventilators are not recent devices. In 1889, Alexander Graham Bell designed and built a prototype iron lung (tank respirator) for newborn infants (O'Leary, King, Leblanc, Moss, Liebhaber, & Lewiston, 1979).

The ventilators most commonly used today are negative pressure ventilators and positive pressure ventilators. Negative pressure ventilators exert negative (subatmospheric) pressure on the exterior chest wall. The pressure creates a suction in the lungs; examples are the iron lung or full body type, and the cuirass, which is a molded plastic shell which covers only the chest (Miller & Keane, 1983). These ventilators require fairly normal lung tissue and so are appropriate when the main problem is muscle weakness, such as muscular dystrophy, or central nervous system malfunctioning as in central hypoventilation. The advantage to these ventilators is that they avoid tracheostomy and the resultant restriction of speech. (However, if a tracheostomy is necessary because of swallowing incoordination or upper airway obstruction, this advantage is lost.) The disadvantage of the iron lung is that it prevents mobility of all body parts except the head. The cuirass is portable and allows mobility of the arms (O'Leary et al., 1979). These negative pressure devices are relatively inexpensive and easy to use (Frates et al., 1985).

Positive pressure ventilators force air directly into the lungs under positive (supra-atmospheric) pressure. For conditions of acute respiratory distress or chronic respiratory insufficiency, positive pressure ventilation is necessary. It is a more powerful means of moving air in and out, and the machinery can be easily transportable. Positive pressure, however, can do harm to circulation and the antidiuretic hormone balance. Frequent appropriate vital measures such as blood pressure readings as well as

accurate record-keeping are required. A mouthpiece can be attached to a positive pressure ventilator, thus avoiding a tracheostomy, if continuous ventilation is not necessary (Frates et al., 1985). If a tracheostomy is necessary, it requires special care (Miller & Keane, 1983).

Intravenous nutrition

Parenteral nutrition is used for children who have a medical or surgical condition that prevents them from obtaining adequate enteral (through the intestine) nutrition for long periods. Children with short bowel syndrome cannot survive without total parenteral nutrition, and there is almost no chance of their intestines growing sufficiently for them to acquire adequate nutrition enterally. Likewise, children with pseudo-obstruction will rarely attain sufficient motility (movement) and absorption to allow enteral nutrition.

By contrast, children with primary mucosal (mucous membrane) disease, if they receive sufficient proper nutrition, may develop normal villi (the threadlike projections in the small intestine where absorption occurs) and then convert to enteral nutrition (Cannon et al., 1980). Children with a lactose intolerance can often be treated with enzyme supplements and diet changes and thus convert to enteral nutrition (Batshaw & Perret, 1981).

Total parenteral nutrition was first described and used as a therapeutic intervention in the early 1970s (Scribner & Cole, 1970). Its practice quickly spread from the Great Britain to Canada and the United States. Important advances have been the development of silastic rubber catheters (rubber-like silicone catheters that are biologically inert) and the acquisition of knowledge about subtle nutritional requirements.

Children receiving total parenteral nutrition have had catheters placed surgically, generally in main veins near the heart or in the thigh. An umbilical catheter is often used with neonates. The onset of use of parenteral nutrition is often during the first two weeks of life, most having started by six weeks, but a few are started during the second year of life and even later (Ralston et al., 1984).

For infants, the original infusion period is for 24 hours. Before the child is released to home care, he/she undergoes a 12-14 day adaptation period to gradually reduce the infusion period to 16 hours. Older children and adults generally tolerate a 10- or 12-hour infusion period (during the night), and babies, between two and six months of age, are subjected to an increasing rate of infusion to decrease the period to 12 hours and to compensate for growth (Cannon et al., 1980). After the 10-12 hours of infusion, a 30-60 minute tapering procedure is required to prevent reactive hypoglycemia (a form of low blood sugar that develops suddenly). Then the catheter
must be disconnected from the infusion system and filled with a special solution to prevent clotting (Mughal & Irving, 1986; O'Connor et al., 1988).

Adults generally require three liters of nutrient solution per day (Mughal & Irving, 1986), although this varies with the person's size and energy output. Over the years, the content of the solution has been changed as medical experts have become aware of inadvertant contaminants such as aluminum and of the need for trace elements such as zinc and copper (O'Connor et al., 1988).

Long-term intravenous drug therapy

Almost all children with cancer receive drug therapy because childhood cancers are more sensitive and responsive to drugs than are adult cancers and because childhood cancers tend to spread early, necessitating systemic treatment. In addition, localized surgery or radiation treatment is used (Serota & Meadows, 1984). Bone marrow transplant is a life-saving procedure for some children, but it requires finding a tissue-identical family member to serve as donor (for which there is a one-in-four chance). Antineoplastic therapy uses a variety of chemical agents to inhibit the growth and spread of malignant cancer cells. Chemotherapy is administered to achieve remission and is continued to maintain remission. If the child suffers a relapse and there are additional chemical therapeutic agents to use, the child is started on a new regimen.

Some chemotherapy is administered orally, other intravenously or intrathecally (intramuscularly). There is some evidence that infusion of the antineoplastic chemical methotrexate improves remission duration and relapse-free survival and reduces testicular relapse rate in children with Acute Lymphocytic Leukemia. Recently, it has been found that slow infusion of certain of these drugs is equally effective to rapid infusion and is less toxic to specific organs.

Until recently, intermittent slow infusions (introductions of liquid into a vein slowly by gravity, as opposed to forcefully by injection) have been performed only in the hospital. This requires a 72-hour stay every six weeks over a two- to three-year period (generally 22 hospitalizations for girls and 31 for boys). Currently, experimental home care programs are being studied. Every six weeks the child undergoes 24 hours of preinfusion procedure at home. On the day of the infusion, the child is evaluated in the outpatient clinic, given an intrathecal (intramuscular) dose of methotrexate, and has a peripheral intravenous line inserted. The child then goes home and undergoes the 24 hours of slow infusion of methotrexate. Preliminary results have been positive in that complications were generally minor, parents reported great satisfaction, and hospital costs were reduced by half (Lange, 1988).

Organicity/Etiology

A wide variety of conditions, diseases, illnesses, and disabilities can create technology dependence. Many of the individual conditions are rare. Other conditions are more common, but only some of the children with the condition require the support of technology.

Children who are ventilator-assisted

These children have respiratory systems that do not function adequately. Some children cannot adequately force the air in and out of their lungs; this can be a muscle problem or a nerve problem that controls the muscles (sometimes termed respiratory paralysis). For other children the oxygen and carbon dioxide within the lungs and the blood system do not exchange sufficiently.

An example of the variety of diagnoses that can result in ventilator dependency was provided by a report on the home care program of the Northwestern University Children's Memorial Hospital (Goldberg, 1984). Of the 18 children released to home care, nine suffered from congenital (inborn) abnormalities. These included myelomeningocele (a spinal cord abnormality), enzyme deficiency, and central hypoventilation (or Ondine's curse, where there is not automatic control of respiration); another four children had experienced spinal cord injuries; two were disabled from surgery or chemotherapy and radiation treatments for malignancies like cancer; and one from infection which resulted in postencephalitis quadriplegia (paralysis from the neck down as the result of an illness that caused the brain to become inflamed and damaged the central nervous system).

In a retrospective report on 101 infants with chronic respiratory failure (a life-threatening inadequacy of the respiratory system, requiring ventilation), half of the infants had a variety of congenital anomalies such as obstructions in the air pathway and heart problems (Schreiner, Downes, Kettrick, Ise, & Voit, 1987). Another 15% had neuromuscular or nervous system disorders, and half of them had severe infant botulism (a severe food poisoning that is different from the adult form). The remaining (36%) infants had respiratory distress syndrome (usually found in premature infants when the system does not produce enough surfactant to keep the air spaces in the lungs from collapsing) and then bronchopulmonary dysplasia (BPD, a chronic lung disease).

In the three-state study of children who were ventilator-assisted (Aday, et al, 1988), half of the children received their primary diagnosis at birth and another 28% were diagnosed before their first birthday. Congenital anomalies and diseases of the nervous system were the two major categories, after BPD. For only 10% of the children did the problem occur after the child reached school age--for many of these children, the cause was accidental injury.

Of the 54 children who were ventilator-assisted in the Frates et al. study (1985), 17 (34%) had spinal cord injuries and almost all had quadriplegia. Twenty-four (44%) had some form of nueromuscular injury (such as Duchenne muscular dystrophy, a progressive crippling disease where the muscles gradually weaken and waste away). Another five experienced central hypoventilation, either congenital or else resulting from encephalitis contracted when the children were infants to eight years of age. Another four were temporarily vented following heart surgery that caused temporary paralysis to the phrenic nerve that signals the diaphragm to contract. Other syndromes accounted for the other four children.

Children Receiving Parental Nutrition

Of the set of children dependent on parenteral nutrition, from the data available (Cannon et al., 1980; O'Connor et al., 1988; Ralston et al., 1984), about half suffer from congenital idiopathic intestinal pseudo-obstruction syndrome (such that the contents of the intestine do not pass through normally) or, less frequently, congenital short bowel syndrome (a maldevelopment of the small intestine so it is too short to allow adequate absorption of the conents). The rest have surgical short-bowel syndrome as the result of surgery to correct a twist in a loop of the intestine or a too-small opening in the intestine.

Prevalence

The number of children in the U.S. who require technology-support is not known. There is no national tracking system for this set of children. Because these children depend on medical intervention, they cannot be unknown to the health
community, but known is not counted. Counting techniques need refinements that exclude those children for whom technology-support has ceased (because of
successful weaning from the support or because of death). The Aday study (1988), for instance, did not make this distinction.

The best estimate of the number of children with technology-support is 2,300 to 17,000, depending on the level of technology needed. This estimate includes 700-2,000 children on ventilators; 350-700 children who receive parenteral nutrition; 270-8,275 children who require prolonged intravenous drugs; and another 1,000-6,000 who require other device-based respiratory or nutritional support, such as tracheostomy tube care, suctioning, oxygen support, or tube feeding (U.S. Congress, OTA, 1987).

One source of numbers for children on home-based total parenteral nutrition (TPN) was the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.). Testimony before the Task Force on Technology-

dependent Children reported that the ASPEN, 1985 registry listed 92 children between the ages of birth and ten years who received parenteral nutrition. Other commercial registries suggested that 300-400 children under 18 years receive home intravenous support (Ziegler, 1988).

Children who are technology-supported are a subset of children with chronic illness. It is estimated that in the U.S. there are 7.5 million children who suffer from a chronic illness. This is about 12% of the population of children under 18 years of age. About 10% or 750,000 of these children are severely affected; about 2% (15,000) or fewer of the severely affected children are supported by sophisticated technology (Hobbs, Perrin, & Ireys, 1985, p. 39).

The number of children who are technology-supported is increasing but not in a simple fashion. Some medical interventions are so successful that children who 10 years ago would have lived seriously restricted lives are today living unencumbered lives. On the other hand, current technology is keeping children alive who would have died 10 years ago. For some of them this entails a continued dependence on technology, but for others the technology-support is only temporary.

Studies of infants in neonatal intensive care units have shown that the proportion of infants who survive with serious disabilities has not increased since the introduction of neonatal intensive care (U.S. Congress, OTA, 1988). (Currently, about 16% of low birthweight infants survive with serious or moderate disabilities.) But in absolute terms, greater numbers of low birth weight babies are surviving, so there are also larger numbers of neonatal intensive care unit survivors with serious disabilities. A subset of these infants are members of the technology-supported group.

A continuing dependence on parenteral nutrition is one possible outcome of neonatal intensive care, especially in the United States. (In Great Britain, there were only three infants among 200 registered parenteral nutrition patients from 1977 to 1986.) This small number, relative to numbers in the United States, has been attributed to differences in approaches to high-technology treatment at the extremes of life; Mughal & Irving, 1986.) A significant number of United States' infants dependent on parenteral nutrition do not survive. The most recent report from the UCLA longitudinal study reports that, of 33 children who entered the program since 1977, 13 (or 39%) had died (O'Connor et al., 1988).

II. HEALTH AND PHYSICAL CHARACTERISTICS OF CHILDREN WHO ARE TECHNOLOGY-SUPPORTED

Demographics

Ages

Data on the ages of children who are supported by technology are scattered and probably are not representative of the population.

Children who are ventilator-assisted. One exception is information from Project School Care in Massachusetts (D. Walker, Personal Communication, April 18, 1989). A survey to identify children with functional disabilities in the state found that Massachusetts had 41 children on respirators; of these, 18 were less than one year of age, one between one and two years of age, seven were three to five years of age, three were six to eleven years old, and eleven were twelve to eighteen years old. The median age group was three to five years.

An earlier study of children on respirators by the Massachusetts Department of Health, which conducted a survey in 1980 of the 14 hospitals capable of caring for infants and children on ventilators (Burr et al., 1983), identified 14 children; eight of them resided at home and their average age was six years.

Of the 141 children included in the Aday et al. (1988) study, only 6% were less than one year old at the time their families were interviewed and almost all of them lived in the state (State C) where three-fourths of the children had been on a ventilator only temporarily (67%), if at all (9%). Across the three states, 35% were one and two years of age and, again, most resided in State C. Another 28% were three to five years of age and this percent was approximately equal across the three states. Another 22% were six to 20 years of age, the percentage decreasing with age (that is, 11% were 6-10 years of age, 7% were 11-15 , and 4% were 16-20 years old). Very few of these older children resided in State C. Nine percent of the children were deceased, and only one was older than 21.

More current data on the Louisiana (one of the states in the Aday study) population of children who were ventilator-assisted showed there were 70 children, ages newborn to 22, served by the SPRANS (Special Projects of Regional and National Significance) program and the average age was six and one-half years. This older mean age is because of the many children with spinal cord injury (K. Kirkhart, Personal Communication, April 20, 1989).

The Texas retrospective study (Frates et al., 1985) reported the age of the child at time of discharge. Of the 54 children, eight were discharged from the hospital before they were one year of age, another ten were between one and five years of age, while 19 were 6 to 12 years of age and 17 were 13 to 18 years of age. Only seven had spent more than one year in the hospital. The longest hospital stay was three years for one quadriplegic child.

Children receiving parenteral nutrition. The technology for total intravenous nutritional support is quite new. Few children have reached adolescence (O'Connor et al., 1988).

Children with cancer. The incidence of childhood leukemia for children under 15 years is approximately 35 per million. The incidence of acute lymphocytic leukemia (ALL, the most common of the childhood cancers) peaks for the three- to four-year age group (Pendergrass, Chard, & Hartman, 1985). The incidence of cancer is increasing, and it remains the highest cause of deaths after accidents among children aged one to fourteen (Travis, 1976).

Gender

A child who is technology-supported is more likely to be a male than a female. The sex ratio varies with the condition; cystic fibrosis, for instance, tends to be evenly split between boys and girls, while head trauma and spinal cord injury are more likely to affect boys (Kleinberg, 1982). Boys are more likely than girls to suffer from the chronic lung disease, bronchopulmonary dysplasia (U.S. Congress, OTA, 1987). Likewise, with childhood leukemia, 20-30% more males than females develop the disease; moreover, the prognosis is poorer for males than females with acute leukemia, in part because the testicles can serve as sanctuary for leukemic cells (Pendergrass, Chard, & Hartmann, 1985). Duchenne or childhood-type muscular dystrophy is found almost solely in boys, while women are commonly the carriers (Miller & Keane, 1983).

Children receiving parenteral nutrition in research. Two-thirds to three-fourths of the children in the UCLA studies of total parenteral nutrition (a maximum of 12 children in a study) were boys, although there were no obvious sex-by-diagnosis trends.

Children who are ventilator-assisted, in research studies. In the Aday study (1988), about two-thirds of the children were male. In the small sample of the Massachusetts Department of Public Health study of children who were ventilator-assisted, there were three boys and three girls (Burr et al., 1983).

Ethnicities

Statistics from neonatal intensive care unit studies find that black babies have significantly lower rates of chronic lung disease than do white babies of the same birthweights (U.S. Congress, OTA, 1987).

Leukemia seems to affect more white children than nonwhites and the mortality rates also are different in that the early age peak has not been found among nonwhite children (Pendergrass et al., 1985).

In the three-state study (Aday et al., 1988), 70% of the children were white, while 24% were black, and 3% Hispanic. This ethnicity mix was influenced by the states sampled. Other factors, such as income levels and cultural values, may also affect the ethnicity statistics.

Physical Health

Duration of ventilator-dependence

Among the children included in the Aday study (1988), almost 60% were born prematurely; across the three states the percentages ranged from 30 to 77%. The program and state with the highest percent of premature births (State C) also had the highest percent of children with a primary diagnosis of bronchopulmonary dysplasia (67%) and the highest percent who had discontinued ventilation (67%).

The other two states, with the lower premature rates among their programs' children, also had low rates of bronchopulmonary dysplasia. Only 9% and 25% of their children had been able to discontinue ventilation, and all of them had been ventilated at some time.

The level of dependence on a ventilator of the children in the Aday study varied. At the time of family interview, 45% of the children had discontinued ventilation, and an additional 5% had never been vented. Of the other half of the children, 23% required 24-hour ventilation. In the two states with older children, half to two-thirds required 13 or more hours of ventilation each day. Relatively few used a ventilator for fewer than eight hours a day.

A study of the Home Care Program at the Northwestern University Children's Memorial Hospital (Goldberg et al., 1984), reported that eight of the sixteen children were on a ventilator for 24 hours per day, and the rest for 16-23 hours per day, although the needs of some of the children varied.

In the Texas retrospective study that reported on children who were released to home care as far back as 1962, 33 of the children required almost full-time ventilator support, while the other 21 did not require full-time ventilation, although specific hours were not reported. Very few of these children were ventilated because of congenital abnormalities. Two of the children with spinal-cord injuries were weaned

from the ventilator, as were two of the children with neuromuscular injuries. All four of the children with temporarily paralyzed phrenic nerves were weaned (Frates et al., 1985).

In the Philadelphia retrospective study of infants with chronic respiratory failure, all the children were ventilated for more than 28 consecutive days (a selection criterion), and the mean duration was 12.3 months. Over an 18-year period, 70% of these infants had survived (Schreiner et al., 1987).

Temporary ventilation of infants

Temporary ventilation is a common treatment for premature infants of low birth weight (less than 2500 grams or 5 pounds, 5 ounces) and of very low birth weight (less than 1500 grams, or 3 pounds, 3 ounces) who suffer from severe respiratory distress syndrome (RDS). RDS is also the primary cause of death among neonates (newborns less than one month old). RDS has occurred in 15-80% of premature infants. The smaller the infant the more likely RDS is to occur. The use of positive pressure ventilators in neonatal intensive care units has contributed to the decrease in severity of RDS and of deaths due to RDS (U.S. Congress, OTA, 1987).

Prolonged use of mechanical ventilation disrupts the babies' normal cardiopulmonary physiology and leads to bronchopulmonary dysplasia (BPD, a chronic lung disease, which is determined by chest radiograph and the fact of ventilation for more than 28 days). BPD is one of the most common outcomes of neonatal intensive care; birth weight is the best predictor of lung damage. About two and one-half percent of infants discharged from the hospital with BPD continue to require respiratory support at home.

Children receiving parenteral nutrition

Parenteral (intravenous, not through the digestive system) nutrition is given to infants and others whose intestinal system does not function adequately to accept or absorb nutrients into the blood stream.

Total parenteral nutrition is also used as a short-term intervention for low birth weight infants who are unable to ingest sufficient calories orally during the neonatal period. As the infants are able to accept increased quantities of oral feeding, the rate of total parenteral nutrition infusions is slowed and then discontinued. It has been hypothesized that this intervention might prevent the later lower IQs of low birth weight children (Tejani, Mahadevan, Dobias, Nangia, & Varma, 1979).

Children with cancer receiving intravenous drug therapy

Long-term intravenous drug therapy has become a common treatment for childhood cancer (usually, acute lymphoblastic leukemia, ALL). By the 1970s, 90 to 95% rates of remission (return to normal bone marrow, blood and/or affected

organs) were experienced by large numbers of children with ALL. Since maintenance therapy (chemotherapy during the remission period) has been instituted, along with the use of more effective antibiotics, the duration of remission has increased (Pendergrass, Chard, & Hartmann, 1985).

Prognosis

The prognosis for children who are technology-supported varies and is best predicted by the etiology and severity of the condition. Severity reflects an interaction between physiological severity and the environment, which includes medical treatment (Stein, Perrin, Pless, Gortmaker, Perrin, Walker, & Weitzman, 1987).

Children who receive ventilator-assistance

Children in the primarily preschool-aged group (from State C in the Aday study, 1988), three-fourths of whom had been born prematurely, were generally expected to improve. Among the group of older children in a different state, half with congenital anomalies and one-third with diseases of the nervous system, only one-fourth were expected to improve, and one-fourth were expected to worsen.

In the Frates et al. (1985) home-care study of older children dependent on ventilators mostly because of injuries and muscular diseases (children with polio excluded), 17 (31%) of the children died. There was an 84% one-year survival rate and a 65% five-year survival rate. Four of the deaths were caused by an unobserved disconnection of the ventilator (and a failure of the alarm to trigger) or an unnoticed night-time power failure. At least half of the deaths were attributable to the progression of the primary illness.

Late effects of polio

Respirators (or negative pressure ventilators, which cause a suction effect in the lungs) were first used extensively for polio victims of the 1930s to 1950s. A recent study of aging effects of a sample of the 1953 Manitoba polio epidemic survivors may be relevant to the long-term prognosis for children who are ventilator-assisted. This was an in-depth study of 10 survivors, who were 8-35 years of age at polio onset; follow-up was performed 30-35 years later. The results showed that the persons who had become largely independent of respiratory support remained stable for several years. But then either suddenly, as the result of a respiratory infection, or slowly and insidiously, they experienced tiredness, lack of energy, and repeated falling asleep during the day. Once recognized, the persons returned to partial and gradually increasing mechanical support. Some had returned to full-time ventilator support to maintain oxygen supply, energy levels, and quality of life. The contemporary explanation for this decline is premature exhaustion of muscles (Locker, Kaufert, & Kirk, 1987).

Conditions Other than Primary Diagnosis

Many children who are technology-supported have additional medical problems /disabilities. Co-occurence of other conditions is probable and is relevant information for schools and other organizations as they make plans for home- and community-based placements and programs.

Children who are ventilator-assisted

Children requiring full-time, positive pressure ventilation generally have a tracheostomy (a tube surgically emplanted in the trachea). A gastrostomy (an opening into the stomach) for feeding also is comon. Co-occurring conditions can include hydrocephalous (a congenital defect that allows fluid to accumulate in the brain), cerebral palsy (nonprogressive brain damage that causes persistent motor dysfunction), seizures, spasticity, and visual acuity problems (Burr et al., 1983).

In the three-state study (Aday, 1988), the caregiver was asked whether the child had additional complicating conditions at the time of interview. About three-fourths of the children had at least one additional condition, with three conditions being the average number reported. These varied from temporary conditions (e.g., ear infections, hernias) to chronic (e.g., diabetes or asthma) to ones that required technology support (e.g., gastrostomy).

Children receiving parenteral nutrition

Children receiving parenteral nutrition are at risk of catheter-related infections and other complications such as anemia and rickets, because of deficiencies in the parenteral nutrition solution. These children may have other problems such as pancreatitis, liver disease, pneumonia, and heart failure (Ralston et al., 1984).

These children are likely to require surgery related to their gastrointestinal disease or malformations. These include bowel or colon resections, colostomies, gastrostomies and cholecystectomies (removal of the gall bladder; see O'Connor et al., 1988).

Children with cancer

Many heritable conditions can predispose a child to cancer, the most common being Down Syndrome, although other chromosomal abnormalities also have a link with leukemia. A variety of immunodeficiency diseases (where the immune response is deficient) also show a heightened association with cancer (Pendergrass et al., 1985).

Hospitalization and Rehospitalization

Children who are ventilator-assisted

These children are at risk of lower respiratory tract infections and hospitalization. The Aday study (1988) found that, in addition to their original hospitalization, about three-fourths of the children had been rehospitalized at least once and one-fourth had three to five rehospitalizations. Children who had been home the longest had experienced the most rehospitalizations. These stays tended to be relatively brief; the majority were for less than a week and 90% were for less than a month. Among this sample, about one in five rehospitalizations was for respiratory distress or pneumonia, and another one in five was for surgery.

While at home, these children tended to see a doctor every other week. Other professionals made home visits, most frequently after the child's discharge, with visits becoming less frequent over time.

The six children in the Massachusetts study (Burr et al., 1983) experienced an average of four rehospitalizations, but the number ranged from none for the two children with late onset disease or injury to 12 for a 6-1/2 year old with a congenital defect.

The children in the Texas study (Frates et al., 1985) averaged less than one rehospitalization per patient per year, generally for cardiorespiratory problems. However, most respiratory problems were handled at home with liberal use of antibiotics; moreover, parents reported fewer respiratory problems at home than at the hospital. The length of the original hospitalization ranged from a few days to three years; although it was rare for a child to have been hospitalized for more than a year.

Children receiving parenteral nutrition

The mean length of the original hospitalization for a set of children receiving total parenteral nutrition was about four months (Ralston et al., 1984). During the first two years, these children averaged five surgical procedures; more than half of these were related to catheter placement. They also averaged seven medical complications over this period, each of which required rehospitalization. Cholestatic (liver-related) jaundice and anemia accounted for one-third of these complications, while rickets occurred less frequently.

The children who were four years old or older by 1988, had spent a mean of 12% of their lives in the hospital--about 8-1/2 months of their lives (the range was two to 20 months). They averaged nine surgeries, half of them for replacement of catheters. The children averaged more than two catheter-related infections and another three, noncatheter-related infections during this period (O'Connor et al., 1988).

This technology is so new that the long-term prognosis is not known. Of the nine children in one of the UCLA longitudinal studies, performed when the children were three years of age, three had discontinued parenteral nutrition because adequate nutrition was achieved enterally (by way of the intestine; Ralston et al., 1984.) By contrast, of the 12 children in the longitudinal study when the children were over four years of age, all but one were expected to continue total parenteral nutrition for the rest of their lives (O'Connor et al., 1988).

These statistics on the prognosis for children who are technology-supported illustrate the problems faced by demographers in collecting accurate data on the prevalence of technology support. Some children are weaned from the technology and some children die. For instance, a small set of children receive parenteral nutrition follow-up care through the UCLA Medical Center. Yet each report in the series, which provides a variety of current measures, is based on a somewhat different population.

Physical Status

The physical status of these children, as a group, has not been reported. A child's particular conditions and severity of disability are major determinants. The variable course of a child's health is another factor; a high frequency of illness and rehospitalization is common for this group.

Children who are ventilator-assisted

Children whose underlying conditions are due to neuromuscular problems may require assistance with ambulation. Duchenne muscular dystrophy, for instance, involves a gradual weakening and then atrophy of muscles. As this progresses, the child is confined to a wheel chair and then to bed. The small muscles are the last to be damaged, so finger use continues. The mind is not affected, although death may occur before 20 years from respiratory ailments or heart failure (Miller & Keane, 1983). Children with central nervous system problems may have movement disabilities (as with myelomeningeocele) or may not (as with central hypoventilation).

The Aday study (1988) did not inquire about the physical status of the children in the three programs. A functional status questionnaire was included in the caregiver interview (which asked, for instance, 'climbs stairs without assistance' and 'dresses and undresses alone'), but as mentioned earlier, the respondent was allowed to reply that a question was 'not applicable.' The averaged results, that the children were performing age appropriate tasks closer to 'all the time' than to 'some of the time,' were not very informative.

For three-fourths of the children, lower respiratory tract infections and rehospitaliza- tions were frequent. The other quarter had not been rehospitalized. (The average child in the Aday study had been home for two years.)

Children receiving parenteral nutrition

As stated earlier, many of the infants receiving total parenteral nutrition are started within the first several weeks of life. Among these infants, variable degrees of protein-calorie malnutrition were evident before the procedure. The UCLA study of the babies at 18 months of age (Cannon, 1988) found that five of the eight children were below the fifth percentile in weight, although their percentiles for height and head circumference were within the normal range. With initiation of total parenteral nutrition, rapid weight gain was observed, most of it during the first four to six months. It was noted earlier that the 4-8 year old children displayed visual-motor integration delays (O'Connor et al., 1988).

Childhood leukemia

Until these children are affected by cancer, there is nothing consistent about their physical development that sets them apart from their peers. Symptoms of cancer are caused by the injury or destruction of normal cells, not by the proliferation of malignant cells. Chemotherapy, radiation, and surgery have significant negative effects on the child's health. Nausea, weight loss, lethargy, and hair loss are common consequences.

Children with very low birth weight

In the Asbury et al. study (1985) the one-third of the children with very low birth weight who exhibited attention deficit disorder (ADD) at two years of age (compared to their peers who were very low birth weight, non-ADD) were also found to have significantly more minor physical/neurological disabilities (30% versus 12%) but not major ones (12% versus 9%). The minor disabilities included muscle tone disorders, vision refractive errors, conductive hearing loss, and minor congenital anomalies. The children with ADD also had a smaller mean head circumference (which had not been the case at birth or at hospital discharge), poorer visual tracking, poorer visual-motor coordination, and poorer gross and fine motor coordination (Astbury et al., 1985).

Temporary total parenteral nutrition

In the study of the children of low birth weight who recieved temporary total parenteral nutrition during the neonatal period and who survived (Tejani et al., 1979), about half were at or below the tenth percentile for height and weight when tested at four to seven years of age. These tended to be the same children who performed poorly on the intellectual tests.

Summary

A higher than average proportion of physical problems is to be expected among children who are technology-supported. Serious physical disabilities are

likely especially among children who are ventilator-assisted and in those with central nervous system injuries or muscular disorders. Extrapolating from related data, a higher than normal incidence of minor physical disabilities may be present among children of very low birth weight who are ventilator-assisted. These may be associated with delays in fine motor and gross motor development and in visual-motor coordination. Children receiving parenteral nutrition appear to display similar patterns.

III. DEVELOPMENTAL CHARACTERISTICS OF CHILDREN WHO ARE TECHNOLOGY-SUPPORTED

Cognitive Characteristics

Most children with chronic illness do not have an intellectual impairment, although school-age children are likely to do less well in school than their healthy peers (Hobbs, Perrin, & Ireys, 1985, p. 108). Among children who are supported by technology, there is a heightened risk for mental retardation among children with central nervous system disorders such as spina bifida or myelomeningocele. But this is not generally the case with disorders such as Duchenne muscular dystrophy or other neuromuscular disorders (Miller & Keane, 1983). For a variety of reasons there may be times of limited alertness and capacity to concentrate (Pendergrass et al., 1985).

Infants who received temporary ventilator-assistance

A follow-up study of prolonged but non-permanent mechanical ventilation of very low birth weight infants found poor developmental progress during the first 18 months of life (Bozynski, Nelson, Matalon, O'Donnell, Naughton, Ushanalini, Meier, & Ploughman, 1987). During a 3-1/2 year period, 243 infants weighing less than 1200 grams were admitted to a neonatal intensive care unit; of these 159 survived. Twenty-seven percent of these infants required prolonged mechanical ventilation. Forty percent of the infants suffered intracranial hemorrhage. Bayley Scales were administered to the very low birth weight survivors at 4, 8, 12, and 18 months, age corrected for prematurity.

Bayley scores for the entire group decreased with age. Moreover, children who received prolonged mechanical ventilation scored lower at each testing than did children who did not receive prolonged mechanical ventilation. Intracranial hemorrhage alone was not related to Bayley scores. The children who experienced prolonged mechanical ventilation were the ones with lower birth weight, younger gestational age, and increased length of hospitalization. Even when these variables were controlled for statistically, ventilation remained a significant predictor of delayed developmental progress.

At 18 months, race also predicted Mental Development Index score in that nonwhites scored lower. In this sample, 80% of the children were nonwhite and their families tended to have lower incomes than did the white children's families. It is well-established that over time medical

factors become less powerful predictors of cognitive outcome, while socioeconomic status and environmental factors gain in predictive power (Sameroff, 1981). Prolonged mechanical ventilation continued to have an impact on the child through18 months of age (Bozynski et al., 1987).

There is some research reporting that effects on cognitve functioning of survivors of bronchopulmonary dysplasia have disappeared by two years of age (U.S. Congress, OTA, 1987).

Children who are ventilator-assisted for prolonged periods of time

In the retrospective study of 101 children who were cared for in the pediatric intensive care unit of The Children's Hospital of Philadelphia, developmental data were available on more than half of them. The ages at testing were not provided. One-third tested within the normal range of intelligence. One-third of the children tested in the borderline and mildly delayed categories, while the remaining one-third were evenly split between moderate and severe delays (Schreiner et al., 1987).

The sparse data on the level of functioning of the children in the Aday study (1988) indicated that they were doing very well. When caregivers were asked to rate their child's performance during the past two weeks on age-appropriate activities (for instance, 'dresses without help,' 'gets involved in games'), the average score was somewhat closer to 'almost always' than to 'once in a while.' A second measure of the child's personal adjustment (for children over five years of age, for instance, 'kept on task even when difficult' and 'spent time with friends') found the children to be performing age-appropriate skills either 'often' or 'almost always'.

The results of both of these scales must be viewed with some caution, because parents were allowed to decide that a question was 'not applicable' to their child (for instance, 'did the child eat well?', when the child had a gastrostomy tube for feeding, or 'attends to his environment for awhile', when the child was in a coma). Since the researchers do not report how often the 'not applicable' answer was given, it is not possible to know how this alternative answer affected the data.

Of the six children in the Massachusetts study, it appeared that the four with congenital or perinatal onset conditions were progressing normally. The two preschoolers were beginning to use signs for communication and the school-age children were using speech. The two children with later-onset central nervous system conditions had no expressive language, although one had good receptive skills (Burr et al., 1983).

Children who received parenteral nutrition

Quantitative data on the cognitive development of these children was supplied by the UCLA longitudinal study of children receiving home total parenteral nutrition. Developmental data were obtained at 4-6 months and at 12, 18, 24, and 36 months. At the youngest ages, the children, on average, were performing in the low normal range on the Gesell Scale; they were low in gross motor, adaptive, and language skills. At 12 months, they scored slightly higher (95, where the mean for the scale is 100, and standard deviation is 10). The children who remained hospitalized or had been home for only a brief time scored lowest.

The set of children tested at 36 months of age (this set overlapped to an unspecified extent with the set just described) showed increased scores from 6 months to 12 to 18 and to 24 months. Considering the children's development over 36 months, the authors detected three distinct developmental patterns (based on only nine children). One set of children scored in the normal range at six months and showed only modest fluctuation through 36 months. A second set performed below normal at six months, but showed rapid improvement to the normal range by 12 or 18 months. These children had experienced prolonged hospitalizations during the first year and it is possible that they had not achieved complete nutritional recovery by six months. The third and most disturbing set were somewhat advanced at six months but then showed a gradual slowing in the rate of acquisition of skills and by 36 months had the lowest scores; it is unclear why. One of these two children showed some brain abnormalities, and he died shortly after reaching 36 months of age (Ralston et al., 1984).

A later study of four- to eight-year-old children in this program (an unspecified number of whom were in the earlier studies) indicated that they were functioning within the average range of intelligence. The children who were six years or older scored better on the verbal subtests than on the performance subtests. However, the majority of these children displayed developmental delays in visual-motor integration (such as the eye-hand coordination necessary for drawing). There was evidence that the older children were experiencing attention difficulties.

It is important to note that one criteria for inclusion in these longitudinal studies was that there be no evidence of central nervous system (CNS) anomalies or insults that might adversely affect developmental capacity or performance. The authors do not report the number of children excluded by this criterion. It is reasonable to assume that such children would perform more poorly on intellectual and perceptual-motor tests.

The children's verbal intelligence scores were unrelated to a variety of medical measures, but were significantly related to the socio-economic status of the families. These are common findings. These children had spent the major portion of their lives at home (they averaged nine months in the hospital or 13% of their young lives). Their home environment (as

gauged by SES) was a better predictor of verbal skills than were their medical experiences.

By contrast, their scores on performance subtests of the intelligence scale and on the perceptual-motor test were negatively related to medical complications of their conditions and to frequency of hospitalization. Children with a high frequency of hospitalization and more severe medical complications tended to score more poorly on perceptual-motor tasks and on nonverbal intelligence test subscales (O'Connor et al., 1988).

Similar deficits have been described in children with a variety of diseases (for instance, Koff, Boyle, & Pueschel, 1977). Other reports of children on total parenteral nutrition implicate contaminants in the solutions and deficiency of trace elements (for instance, Griswold, Reznik, Mendoza, Trauner, & Alfrey, 1983). In the O'Connor study (1988), the younger children displayed fewer problems, perhaps because there were fewer medical complications because of their relative youth or because they had received improved total parenteral nutrition solutions and techniques. Another possible explanation is that they were tested with different scales (WPPSI rather than WISC-R).

Childhood leukemia

Children with Down Syndrome show an increased chance of contracting leukemia (Pendergrass et al., 1985), but otherwise children are neither predisposed to nor protected from cancer on the basis of intellectual functioning. Cognitive effects of long-term intravenous drug therapy are believed to be minor and transient and due to induced lethargy and nausea.

Additional relevant information is available about children similar to children who are technology-supported. The results of these related studies indicate areas of interest for educational planning and future research.

Children with chronic illness

Data on these children (of whom children who are technology-supported are a subset) show that by school-age and as a group, they experienced difficulties. A study of school-age children with long-term illness found that at least one-fourth were performing well below grade level (Sultz, Schlesinger, Mosher, & Feldman, 1972).

A separate study of children who suffered severe head trauma found that only 16% were able to return to normal school classes and that mental retardation was a serious residual effect (Travis, 1976).

In earlier studies of the effects of hydrocephalous, 18% had both normal intelligence and a mild to moderate physical disability, but 33% had a combination of severe physical and mental deficits that would require life-

long care (Lorber, 1972). (Children with hydrocephalous form only a small percent of the children who are technology-supported.)

Children with very low birth weight

A study of 213 two-year olds with very low birth weight in Melbourne, Australia (Astbury, Orgill, Bajuk, & Yu, 1985), found that 34% of the children were diagnosed as having attention deficit disorder (ADD). An important neonatal antecedent of ADD for these children was bronchopulmonary dysplasia and a longer period of mechanical ventilation. Generally the children with ADD experienced a more problematical neonatal course. Although there was no mention that any were currently ventilator-assisted, some may have been since about 10% had major disabilities, including quadriplegia, cerebral palsy, and seizures.

The two-year olds with very low birth weight who were not diagnosed as having ADD earned a mean Bayley Mental Development Index score of 104, while the children with ADD achieved a mean score of 85 (more than one standard deviation lower). Mothers of the children with ADD were less likely to have reported that their child had a favorite book at home than were the mothers of the children without ADD. The Physical Development Index scores were low normal and did not differ between the children with and without ADD. Children with ADD are at high risk for school-age learning disabilities (Astbury et al., 1985).

Neonates with low birth weight and temporary total parenteral nutrition

Early studies have shown that babies of low birth weight are at risk of lowered IQs and retarded growth. Tejani et al. (1979) reported results of a study of children to whom temporary total parenteral nutrition was provided during the neonatal period. Some of these neonates had been of normal birth weight. Follow-up at 4-1/2 to 7-1/2 years of age was possible on 26 of 34 of these children.

At follow-up, one-third of the children with low birth weight had IQs below 90. This did not differ from the proportions found in other studies of children of low birth weight who had not been treated with total parenteral nutrition. The researchers expressed disappointment that the use of total parenteral nutrition with infants of low birth weight did not reduce the incidence of low IQ. The socio-economic statuses of the families were not reported. Since a relationship is generally found, it might have been significant to show that SES was not confounded with IQ. The children with low birth-weight also performed poorly, compared to control children, on the Bender-Gestalt test of visual-motor coordination and on the draw-a-person test.

Summary

Children who are technology-supported, as a group, are expected to fall within the normal range of intelligence. For children who are ventilator-assisted there are no results of standardized cognitive tests on large groups. We are dependent on tentative extrapolations from available data. Children who were begun on a ventilator because of Respiratory Distress Syndrome and low or very low birth-weight are likely to show delayed cognitive development during the first two years and possibly longer. Long-term hospitalization would account for at least some of this delay. The general rule, that with increasing age medical conditions become less good predictors and family SES becomes a better predictor of cognitive level (especially verbal IQ), is likely applicable here. Children receiving total parenteral nutrition display a similar pattern of early cognitive delays that, with age, disappear or interact with environmental effects.

There is some indication for both children who are ventilator-assisted and children who are receiving total parenteral nutrition, that Performance IQ and visual-motor integration may be a longer-lasting problem. Attention Deficit Disorder (or milder attention difficulties) also appear to be more likely than in the average child.

Temporary limited alertness is to be expected from drug effects or illness. Children who are technology-supported are particularly susceptible to illness and in need of medication.

Socio-emotional Development

Quantitative data in this area are few because of the absence of valid, reliable, well-accepted measures, because of the recency of interest by researchers, and because of the unavailability of children to test.

Children who are ventilator-assisted

In the Aday study (1988) the caregivers of children over five years of age completed a revision of the Personal Adustment and Role Skills Scale (Goldberg et al., 1984). These children were reported to be functioning very well. The mean score over the six subscales was 3.5 of a possible 4, indicating the children were performing age-appropriate social behaviors either 'often' or 'always.' The children, as a group and during the past two weeks, were showing appropriately low levels of hostility, dependency, withdrawal, and anxiety depression.

On two subscales the children were rated as performing less well. On the peer scale (which asked, for instance, 'joined others of own accord, 'and 'had many different friends'--only four items in the scale), the mean score was 2.7 (between 'sometimes' and 'often'). The average score was lowest (2.5) in State A which had more older children than did the other two states. These data indicate that peer relationships may be a problematic area for children who are ventilator-assisted. These results are based on 34 or fewer children, since the 'not applicable' response led to the deletion of an unspecified number of children from the analyses.

The caregivers also rated these children somewhat lower on the productivity subscale (2.9). The four questions in this scale inquired about staying on task and doing work without being pushed.

Children receiving total parenteral nutrition

Apparently, no studies have addressed the socio-emotional development of children receiving total parenteral nutrition.

Children with cancer

Studies of children with cancer, although not specifically of children receiving long-term intravenous drug therapy, are more common. Generally, they report stress effects upon diagnosis and during treatment and difficulties returning to school. As the length of remission has increased, longer term effects such as adult relationships, marriage, and the decision to have children are receiving attention (Tebbi & Mallon, 1987).

IV. CHARACTERISTICS OF FAMILIES WITH CHILDREN WHO ARE TECHNOLOGY-SUPPORTED

Demographics of Families

Children with ventilator-assistance

Family composition. The families of the children in the Aday et al. study (1988) were very likely to be two-parent families. Only 12% of the children who were released from the hospital to home care returned to single-parent homes. Another 20% moved into extended family living arrangements with one or both natural parents present. The other two-thirds returned to two-parent homes.

Most of the families in the Aday study had two or three children; however, 30% of the sample had only the one child. When there were siblings, the child who was technology-supported was usually the youngest. However, one in four of these families included at least one other child younger than the child who was technology-supported.

In the study by the Massachusetts Department of Public Health (Burr et al., 1983) of six families providing home care for their child with ventilator-assistance, four of the families had older children (range was 1 to five); none had younger children. The families reported they did not feel they were in any position to care for additional children.

Age of parents. The average age of the primary caregiver in the Aday study (99% of whom was the mother) was 31 years; the average age of the other caregiver in the home (73% of families had at least one other) was 34. The other caregiver, in 7 of 10 homes, was the father; some other relative accounted for most of the remainder. Only four children were not placed with relatives.

Socio-economic status. Among Aday study participants, the educational level of the adults in the home was somewhat above the national average; 91% of the principal caregivers had completed high school, and 16% had also completed college.

In 1986 dollars, about half of the families in the Aday study reported incomes under $25,000, and one-third reported incomes below the poverty level. Not all families were doing so poorly; about 20% of the families reported incomes over $40,000.

Ninety percent of the Aday study families had one or more members in full- or part-time work. In more than half of these families, the principal caregiver (the mother) was not employed outside the home; in only one-fourth of the families was she employed full-time. Most of the mothers had been employed formerly; more than half reported quitting their jobs because of their child's illness.

The other caregiver (usually the father) was employed in 80% of the families. Half were in blue collar jobs and almost one-third were in professional positions.

The Texas retrospective study of children with ventilator-assistance in home care noted that 90% of the parents had been judged to be middle or upper middle class. More than 80% were two-parent families, and 80% had at least one parent who had graduated from high school (Frates et al., 1985).

Children receiving total parenteral nutrition

Family composition. Among the UCLA study families with total parenteral nutrition (Cannon et al., 1980), eight of nine were two-parent families. One of these children was fully cared for by the maternal grandparents. There was only one single mother. By contrast, 19% of American households with children were maintained by single mothers (Thornton & Freedman, 1983).

In one of the UCLA parenteral nutrition studies (Ralston, O'Connor, Ament, Berquist, & Parmelee, 1984) and using Hollingshead categories, the nine families were arrayed with two in the highest level (based on father's occupation and mother's education), four in the next highest level, one in the third level, and two in the lowest category. This distribution approximates a bell-shaped curve. One of the families in the lowest category was a single mother who received public assistance.

Summary

The demographic data on the families providing home care for their children who are ventilator-assisted indicate they were somewhat better off than the average American family in terms of income and education. This was the case despite the fact that a greater-than-normal percent of mothers did not work outside the home. The child with ventilator-assistance was likely to have older but not younger siblings.

The little demographic information available on children receiving total parenteral nutrition indicates similarities with children who are ventilator-assisted, particularly in the high proportion of two-parent families.

When compared to the larger groups of children with chronic illnesses and other disabilities which these children overlap, the children who are technology-supported stand out with respect to the high proportion of two-parent families and extended-family living situations. In a recent review of the literature on the relationships between marital adjustment and chronic illness, it was reported that
divorce rates in families of children with chronic illness were not different from control families (Sabbeth & Levanthal, 1984).

Socio-emotional Characteristics of the Family

One source of agreement among researchers who study families of children with disabilities is the potential for stress. Hobbs, Perrin, & Ireys (1985, p. 67) observed that studying the psychological consequences of chronic illness is like aiming at a moving target. Effects on the family change as the needs and demands of the child change (Aday & Wegener, 1988). Effects also change with acquisition or loss of supports.

Children who are ventilator-assisted

The Aday et al. study (1988) administered two standardized scales (Stein & Jessop, 1984) to assess the stress experienced by the caregiver and the family. The interviews were conducted after home care was initiated, so (according to researchers) times of acute stress were not studied; rather, these data measure the chronic, everyday stresses the caretakers and families experienced.

The family impact scale included items such as 'having to make last minute changes in plans because of child's state' and 'people in the neighborhood treat us special.' On a four-point scale from 'strongly disagree' to 'strongly agree,' the average overall score was 2.6, which showed that families were more likely to agree than disagree that their child's illness had an impact of the family. Most of the subscale scores also hovered around the midpoint. Subscales queried financial support, general impact, disruption of social relations, coping, and sibling impact.

On only one subscale did the primary caregivers give extreme answers; this was on the family's ability to cope. They were asked, for instance, about 'being a
closer family' and about the caregiver 'feeling better about herself.' The caregivers generally agreed and some strongly agreed with these statements.

Unfortunately, this was the only subscale of five that was composed of questions stated positively. All questions on all the other subscales were stated negatively. Thus there is the possibility that the respondents were inclined to agree with most statements. If that was not the case, however, it is significant that the caregivers felt strongly that providing home care for

their child who was ventilator-assisted had a positive effect on the family's ability to cope.

A separate scale of the caregiver's well-being over the previous two weeks was also administered. Questions included, how often she 'has trouble concentrating,' 'loses her temper,' 'is critical of others.' The average score was close to 'once in a while', indicating that, as a group, the caregivers were not enormously stressed. There was little variation across the three sites or across the subscales, but great variation for individual items. The authors conclude that the caregivers report periodic occurrences of the symptoms included in the instrument.

The evaluation team used these two measures of family and caregiver stress in statistical analyses to determine which, of the many measures they had taken, would predict high and low stress among families and caregivers.

The best predictor was whether or not the family had stated that finances were a serious problem once the child was home. The caregivers with more money concerns were more likely to report that their family felt stressed and that they themselves were less well-adjusted.

Family stress also increased with the number of times the child had seen a physician since hospital discharge. This may be another financial-based issue, a health issue, or a function of timing. Related data show that contact with physicians and other professionals is most frequent shortly after hospital discharge. The first year after hospital discharge can be financially the rockiest, as families await reimbursement for equipment and the working out of financial issues.

Family and caregiver stress did not increase with the number of hours the child was on a ventilator. (It is possible that a measure of the stability of the child's medical condition would be more related to the felt stress of the caregiver.) Likewise, the prognosis for the child (on a three-point scale, as reported by the caregiver) was not neatly related to family stress or caregiver adjustment.

Youths and young adults with progressive neuro- muscular diseases who are ventilator-assisted

A qualitative study of parents of youths mainly diagnosed with Duchenne muscular dystrophy and of the youths themselves provides information on the stresses experienced by families as they decided to use ventilators to improve the person's quality of life (as well as to extend the person's life) and also as they adapted to its restrictions on their lives (Miller, Colbert, & Schock, 1988). Most of the respondents reported choosing to use the ventilator to improve the quality of life rather than as a life-extending aid.

Before initiating use of a ventilator, the children reported feeling tired, 'nodding off in mid-sentence,' and feeling 'crazy' and depressed as they experienced respiratory failure. The parents reported sleepless nights as they tried to make their child more comfortable.

After a ventilator was in use, parents reported stresses associated with: the demands of continuous care and less time for family; increased isolation; friends who were uncomfortable around a ventilator; having to forego vacations because of nontransportability of the machine; efforts to avoid respiratory infections; difficulties associated for caring for an ill patient; lack of privacy due to presence of overnight care providers; equipment breakdown; and anxiety about the future.

Financial worries were greatest for families with commercial insurance, which tended to have a preset cap on total payments.

The persons who used the ventilators reported similar stresses and also distress over not feeling able to reach their full potential, educationally or vocationally. However, they also reported feeling better physically and mentally. All respondents agreed that night-time care was easier.

The trade-offs were especially salient to these respondents, and although the ventilator was associated with many problems, none reported regret about the decision to use the ventilator. In fact, at the two area Muscular Dystrophy Association clinics from which this sample was drawn, every family that had been offered a ventilator accepted it.

Almost all the respondents felt that counseling should have been offered. Only one family was referred to counseling by the health care team.

The retrospective Frates et al. study (1985) reported that the parents needed counseling over the years although these were anecdotal data. Only two of the 54 families refused to attempt home care, and another two families, after three and 14 years of home care, transferred their children to nursing homes because of their increasing inability to manage the child at home.

Children with multiple/physical disabilities

The parents in the Palfrey et al. survey of children in special education (1989) were asked about the effect of their child's disability on a variety of family domains. Unlike Aday's et al. questions, these were not limited to the past two weeks.

Almost two-thirds of parents of children with physical/multiple disabilities reported an effect in at least one area, while the average across all disability areas was only 28%. More than one-third of the families with

children with physical/multiple disabilities reported problems obtaining child care, compared to the average of 12%. Almost as many (31%) reported the child's disability affected the parents' job situation. Fifteen to eighteen percent reported an effect on family/friends, house/community, and marriage. Twenty-five percent reported that their child's disability had an effect on their vacation plans.

Within each disability group (including physical/multiple disabilities), the higher the mother's education, the more likely the family was to report stresses. Three possible explanations for this finding were suggested: (1) more highly educated parents were relatively freed of economic and related stresses and so could focus on the problems due to their child's disability; (2) more highly educated parents were more likely to engage in the process of diagnosing their feelings of stress; (3) these parents were more likely to have had high aspirations for their child which would not be achieved and this differential between aspirations and likely accomplishments caused stress. In this study, the probability of reporting negative effects also increased with the severity of the child's disability, within each disability group.

Summary

The little systematic information available about the socio-emotional characteristics of families with children with technology-support in the home indicates that they are not enormously stressed, at least on a day-to-day basis. This is consonant with the findings on families of children with chronic illness. Not surprisingly, financial problems and health concerns are the best predictors of level of stress. It may be that the first year of home care is a particularly stressful period, because of health concerns, financial issues, and family adjustment processes, although the data have not been gathered directly to test this supposition. Families that have a member with a progressive disease experience similar stresses.

V. RELATIONSHIPS WITHIN FAMILIES WITH CHILDREN WHO ARE TECHNOLOGY-SUPPORTED

The life experiences of children who are technology-supported (and of their families) have not often been the subject of research because parents protect their families from intrusion and because until recently these children have been of concern almost solely to medical researchers. Quantitative data are not readily available, because large samples are difficult to access. Fortunately, some numerical and qualitative data are available. Considerably more is known about the larger group to which they belong, that of children with chronic illness.

When families are the subject of research and when the gathered information is generalized and applied, a number of methodological issues need to be addressed. Reports by the primary caregiver in the family are the most common source of information. It is important to remember that each member of the family has different perspectives on events and different interpretations of experiences. Were each family member to be interviewed, common elements as well as many noncongruent factors would be found (Thomas, 1987). It also is thought that, although the primary caregiver is probably the best single informant for the family, she (less often, he) is not a fully objective, unbiased reporter.

A systemic issue should also be noted. Much of the following information has been gathered to determine the effects on the family of rearing a child with technology-support in the home. Having the child in the home is not the only way in which these families differ from other families. There are other confounding factors. There were precipitating factors in these families that were causally linked to the condition under study. For instance, premature birth is more likely to occur in families of lower socioeconomic status. When examining the impact of the child in the home, it is easy to lay blame on the child rather than on the underlying factors (Thomas, 1987). Family members, themselves, are known to make this misattribution (Intagliata & Doyle, 1984).

Background on Family Systems and Functioning

There is some agreement that a well-functioning family: has open and clear communication; has well-defined boundaries; is adaptive and encourages growth of independence; is supportive of each other; functions effectively and efficiently together including in conflict resolution (Walker & Crocker, 1986). Every family brings its own strengths and vulnerabilities to events and the events themselves weaken or strengthen the family system. It is generally agreed that the degree to which a family unit is functioning successfully before a crisis occurs plays a major role in weathering a crisis and accommodating to change (Critchley, 1982).

The family is a system. Events that affect one family member impact on other members also. Each family is unique and dynamic (Minuchin, 1974; Carter & McGoldrick, 1980). A family with a child who is technology-supported is composed of several possible subsystems. There are the parental, the marital, the sibling, and the extrafamilial subsystems (Turnbull & Turnbull, 1986). Study of each of them is necessary, although not always sufficient for understanding the family (Walker & Crocker, 1986).

Parent-Child Relations

The age of onset of the illness has important implications for the child's and family's life experiences, as does the prognosis for the child.

Diagnosis and initial hospitalization

Many children who are supported by technology are placed on technology at birth. This proportion seems to be increasing.

Children who are ventilator-assisted

Parents in the three-state study (Aday, 1988), when asked to recall their greatest concerns during their child's initial hospitalization, reported they were most often concerned about their child's survival, the critical nature of their child's treatment, and the competence and availability of the hospital staff. Four of five parents reported at least one of these concerns. They also reported family-oriented concerns about the impact of this child on the family as a whole and particularly on siblings. More than 40% of the parents worried about their personal ability to care for their child. Some worried that this care would consume their lives.

Children who are medically fragile are kept in the hospital at least until they stabilize. Premature infants must gain weight and develop to the point that attempts can be made to wean them from life-support systems, such as a ventilator. Infants with myelomeningocele or hydrocephalus usually must undergo the first of possibly several operations.

Many families had to accept long-term hospitalization as the immediate outlook for their children. This required a major reorganization of home life to allow parents to be in attendance at the hospital. When there were older siblings, arrangements had to be made for their care. Additionally, arrangements for missing work had to be made, as well as arrangements for financing the care of the infant. If the infant was in a tertiary care hospital many miles from home, the time and expense of keeping contact with the newborn was even more demanding (Kleinberg, 1982).

Many children with ventilator-assistance in the Aday study (1988) spent their infancy and, some, their toddlerhood in a hospital. In the state with predominantly older children (average age of seven years), the average

length of predischarge stay was 15 months, and 15% of those children had been in a hospital continuously for more than two years. (Another 4% across the three states had never been discharged from the hospital.) For more than two-thirds of the ventilated children who were hospitalized, an intensive care unit was home; usually this was because of the technology involved, rather than the acuteness of the child's illness.

Parenteral nutrition

Children in the UCLA total parenteral nutrition study stayed in the hospital from two to six months (Ralston et al., 1984).

A child growing up in a hospital setting is at risk for the 'hospitalism syndrome' pointed out by Spitz in the 1940s; this is characterized by apathy and depression. The intervention is environmental stimulation and attachment to a significant caretaker. Optimally, the intervention takes place during the first year of the child's life. Some of the children in the UCLA study showed sterotypic behaviors, social indiscrimination, or withdrawal and apathy during their hospitalizations (Ralston et al., 1984). These effects appeared to be caused by the hospitalization or the acute illness--likely both. The authors reported resolution of the atypical behavior patterns after the children adjusted to home life.

Discharge to home

There is a trend for earlier discharge of children who are technology-supported to their homes and families (U.S. Dept. Health & Human Services, 1987). In two of the states in the Aday et al. study (1988), the children had been hospitalized for an average of eight months when they were discharged to home care. Similarly, the six children in the Massachusetts study were discharged, on the average, at nine months of age (Burr et al., 1983). Children dependent on total parenteral nutrition were usually released earlier, on the average, at 2-6 months of age (Ralston et al., 1984).

Considerable preparations and adjustments in family life are necessary. For the parents, sleeping arrangements may need to be revised if there is night medication or a need for alertness. Special diets may need to be established; extra housekeeping chores may need to be added; and hours of special therapy may need to be worked into schedules.

Parents in the Massachusetts study reported a disruption of their sleeping patterns and a period of adjustment to difficult schedules (Burr et al., 1983). The fact that power outages during the night and failure of alarms to signal a disruption of ventilation occur relatively rarely is not completely reassuring to parents, nor conducive to a good night's sleep (Frates et al., 1985). Similarly, children requiring parenteral nutrition during the night must have their catheters cared for and be connected to and then disconnected from the constant infusion pump (O'Connor et al., 1988).

Child-rearing

Children who are ventilator-assisted

In the Aday et al. study (1988), parents were asked about the greatest benefits from having their child home. Almost all commented about the positive aspects of home care versus hospital care. Most spoke about the value of being a "normal" family again. Some families noted that life was better for the siblings. About one-third of the families believed that their child's emotional state was much improved. A smaller number reported that their child's medical status was improved. Gaining control over their child's life was very important to one-fourth of the families. One in ten of the caregivers noted that they personally were more satisfied and had experienced growth.

In the Massachusetts study of six children who were ventilator-assisted (Burr et al., 1983), each family said that bringing their child home had a beneficial effect on family relations because long-term daily hospital visits had been strenuous and had imposed difficulties on the other children in the family. They believed their family had been drawn together by having their child at home. They also reported that the siblings' activities at times were curtailed and parents' social lives were limited. Another common problem was loss of privacy because these families reported having significant levels of home nursing care.

The Aday study (1988) also provided information on the problems and concerns of the caregivers when the child had been home for an average of two years. A small percentage of the families (13%) denied experiencing any problems once the child was home. The most frequent specific concern was the child's continued survival; for one-third to one-half of the respondents in each of the three states, this worry continued. And twenty percent expressed concern over their child's long-term development.

Other concerns included personal and family concerns such as feeling overwhelmed by the responsibility of caring for their child or feeling trapped and unable to leave the home. This was reported by almost one-third of the families (Aday et al., 1988).

In the Aday study (1988) financing was a major problem, as was concern about the availability and competency of nursing professionals and about equipment. Other concerns, reported in a different context, were the lack of privacy in the home and authority/responsibility issues between themselves and nurses. (For caregivers without nursing care, a sense of abandonment and oppression was more likely a problem.)

In a small qualitative study (P. Walker, 1988b) of mostly young children with chronic illness (some with ventilator-assistance), family members noted their frustration in not being able to elicit a desired response from their child and their disappointment in their failure to develop a normal reciprocal relationship. Parents also focused on the positive aspects of

care. A most powerful motivator for several families was the child's obvious need for the parents' care and love. The growing attachment to their children sustained many parents but also made the child's illness more painful. Some parents reported feeling guilty at not having been able to protect the child from the illness (and sometimes, from death) and over leaving the child with a nurse. One mother said she had not been out for four months except to do the shopping, and another family reported not having been away for a weekend for three years (P. Walker, 1988b).

Conditions of children with technology support can often have effects to which the appropriate responses are not obvious. Children who do not receive their nutrition orally, for example, miss opportunities for fine motor skill development of holding their bottles or of picking up food and getting it to their mouths. They generally show a persistent disinterest in food, even though they will sit at the dinner table for social purposes (Cannon et al., 1980). They will do most of their urinating during the night when the nutrition solution is infusing (Berry & Jorgensen, 1988), which can make the development of bladder control more difficult to achieve. Children with myelomeningocele are often unable to achieve control of their bowels and bladders. These are acts that signify independence to many preschoolers.

The families in the Massachusetts study of children with ventilator-assistance, for instance, reported feeling confident in their skills as medical-care givers but much less secure in their knowledge of their children's developmental and educational needs (Burr et al., 1983).

Children with chronic illness. In a study of parents with preschool-aged children with cystic fibrosis, compared to a control group with healthy preschoolers, the parents of the children with cystic fibrosis reported fewer child-related problems than did the control parents. The authors suggest a 'contrast effect' in that normal developmental stresses are experienced as less problematic to families who have already confronted a serious disability in their child. Moreover, the fathers of the children with cystic fibrosis reported better adjustment than did the control children fathers (Cowen, 1985).

Children with physical/multiple disabilities. In the large national study on the implementation of the Education of Handicapped Act (Palfrey et al., 1988), 38% of the parents of children with physical/multiple disabilities reported difficulties in obtaining child care. Twenty-five percent reported that their child's disability had affected vacation plans. Thirty-one percent said it affected their job situation. Eighteen percent said it affected their choice of house and community.

Home care versus hospital care

The three-state study (Aday et al., 1988) provided a statistical analysis of the factors that predicted which children in this sample were doing relatively better at home than while they were in the hospital. In general, the children who showed the most improvement (as judged by the caregiver) were children whose conditions were the least severe; that is, they were ventilated for reasons other than traumatic injury or accidents,

their overall prognosis was not to get worse, and they had shorter stays in the hospital before being discharged to home care.

This analysis also found that males were more likely to show a greater improvement at home, but this also appeared to be due to their condition, which more often was bronchopulmonary dysplasia, for which the prognosis is good. Children who had been at home for longer periods also showed greater improvement, but it is not safe to say that home care was responsible because these children also had more time to mature, their diseases were farther along their courses, and the caregivers had to remember back a longer time to make their judgments. A separate statistical analysis predicting which children were functioning at absolute higher levels found similar factors.

Spouse Relationships

There is very little information on husband-wife relationships in families with children who are technology-supported. This area was not addressed in the Aday et al. study (1988), nor in the few studies of children receiving total parenteral nutrition. As reported earlier, these families have a high proportion of two-parent families.

Children who are ventilator-assisted

The Aday study (1988) finding that the mother was almost always the primary caregiver is consistent with other researchers' observations. Walker (1988b), in her small qualitative study, noted a difference in how quickly and to what extent the father participated in the child's care. For some mothers, this heavier burden was overwhelming, while others experienced it as the opportunity for greater closeness and sensitivity to their child. This differential shouldering of the child care responsibility is normal in our culture, so we should not necessarily expect it to cause marital friction.

Children with cancer

A study on the relationship between parental communication patterns and parental psychological well-being of 26 pairs of mothers and fathers of inpatient children with cancer found that mothers communicated more often and more openly with the child than did the father and also judged the child to be better adjusted. The mothers also judged the family emotional climate more positively than did the fathers. Open and frequent communication showed a positive relationship with the emotional well-being of mothers (Shapiro & Shumaker, 1987).

In a study of strategies for coping with their children's cancer, most married couples (of 32 interviewed) reported that family cohesion was strengthened by their experiences and that their spouses were the most important source of social support. However, among families with greater numbers of child hospitalizations, the perception of spouse support and of marital quality was different for husbands and wives. The wife perceived

her husband as being supportive when he was involved in the child's care, while the husband perceived his wife as being supportive when she was available at home rather than being at the hospital (Barbarin, Hughes, & Chesler, 1985).

Children with physical/multiple disabilities

In the Palfrey et al. study (1989) only 15% of the parents of children with this set of disabilities reported a negative impact on their marriage. This was a higher percent than reported marital problems among parents of children with less severe disabilities but lower than the researchers had expected.

Sibling Relationships

As in any family, children affect their families in a many ways. Siblings can be sources of support for the parents and providers of peer interaction for the child who is technology-supported. They can provide family identities separate from that of a family with a child who is technology-supported. Additional children require additional care, however, so parental fatigue is one of the costs of a larger family, as is a lowered per capita income (Kleinberg, 1982).

There is no overriding theory about chronic illness and sibling relationships. Findings are often contradictory because of methodological problems, such as small sample sizes, using parents as informants, cross-sectional not longitudinal data, etc.. Problems arise in the complexity of the topic, such as the reciprocal nature of the sibling-patient relationship, changes in relationships with age and patient's condition, and interaction effects with parental adjustment (McKeever, 1983).

Children who are ventilator-assisted

More than half the families in the Aday et al. study (1988) had older children. In one-fourth of these families another child was born after the birth of their child who was technology-supported. Caregivers reported that siblings were not negatively affected by the presence of their sibling with ventilator-assistance. The four items in the subscale asked about fighting amongst the siblings, fear of the ill child, increased illness, and lowered school grades. The respondents tended to disagree that these had occurred during the past two weeks.

Children with cancer

There is some evidence of negative effects on siblings. An early longitudinal study of siblings of children with cancer found that measures of self-concept became lower as the sibling's disease progressed and also that siblings scored lowest on personal adjustment measures when the ill child was in remission (Voysey, 1972). Problems included sleep

disturbances, headaches, and preoccupations with their own health (e.g., Burton, 1975).

Children with chronic illness

There is general agreement that the presence in the family of a child with chronic illness has significant effects on the healthy siblings.

There is evidence that many siblings experience neither pathology nor maladjustment. Positive benefits accrue to the healthy siblings. In a study (noncomparative) of siblings of children with cancer, the siblings were noted to be compassionate, tolerant, empathetic to parents, and appreciative of their own good health (Iles, 1979). Interviews with 19 siblings (ages 7-16 years) of children with cystic fibrosis found little evidence for negative effects on the siblings, while there was evidence of personal growth and increased family cohesion (Harder & Bowditch, 1982).

On the other hand, sibling illness was one of the most stressful life events in a study of the etiology of childhood disease (Coddington, 1972). If there is financcial stress because of the child's illness (which is common among children who are technology-supported), this impacts the healthy siblings.

Time the parents allocate to the child who is ill is time not available to other siblings. (This was reported as a problem by parents of older children with Duchenne muscular dystrophy and related disorders; Miller et al., 1988.) There evidence of communication restriction about the sibling's illness between parents and children who are healthy (Burton, 1975).

Some studies have found nonintuitive relationships between the severity of the illness and sibling adjustment. Among children with spina bifida, siblings of children with slight disablities were most disturbed, followed by siblings of the children with severe disabilities, and then with moderate disablilities (Tew & Lawrence, 1975). In a different study, the siblings of children with visible disabilities showed the higher rate of psychological adjustment problems (Lavigne & Ryan, 1979).

Extended Family

Children who are ventilator-assisted

As noted earlier, about 20% of the families in the Aday et al. (1988) study lived in an extended family. Some were single parents residing with relatives, but there were also two-parent families residing with their parents. This high percent of extended family living arrangements is attributable to the needs for additional caregivers for the child with ventilator assistance, additional space for equipment, and cost-sharing.

In the Aday study's multivariate analysis of predictors of caregiver stress, a positive relationship was found between caregiver stress and an extended family living arrangement. The mother reported more symptoms

of stress when she lived in an extended family than when she lived with her husband and children or if she lived as a single parent with her child(ren).

The Aday et al. (1988) survey also found that 31% of the families had trained caregivers (usually only one) who lived outside the home. These caregivers tended to be the child's aunt, grandmother, or married sister.

In her qualitative study of five families, P. Walker (1988b) found wide variation in the amount of support provided by the extended family. None of the families lived in an extended family arrangement. Rarely did the members of the extended families provide direct care to the child. The mothers interpreted this lack of assistance as 'not caring' or as being unwilling to acknowledge that a problem existed. Extended family members more often provided assistance by taking care of the other children in the family.

Summary

The problems families experience have been described, but little is known about the prevalence of individual problems or which families experience what problems. Something is known about the parents' positive valuation of rearing the child at home. There are no data (either quantitative or qualitative) from the child's point of view on experiences with parents or siblings. Information about the parent-child relationship itself and characteristics of day-to-day interactions are not available. Although two-parent families are common, little is known about spouse relationships. Extended family relationships have both positive and negative effects.

VI. INTERACTIONS OF FAMILIES WITH CHILDREN WHO ARE TECHNOLOGY-SUPPORTED WITH PERSONS AND AGENCIES OUTSIDE THE FAMILY

Home care for children who are technology-supported requires assistance from and accommodation by many groups outside the family.

Medical/HumanServices

Families with children who are technology-supported as a group have longer-term and more intensive contact with the medical world than do other families. The meshing of a family with the bureaucracy of medical institutions is rarely fully satisfactory and relations with individual health care professionals vary greatly.

Diagnosis

Abundant qualitative research exists on the stress experienced by families at the time of diagnosis of their child's disabilities. The concept of stages of adjustment to this stress is accepted by many, although data to support a specific sequence are generally absent (Blacher, 1984). Some therapists and likely some parents find it a useful concept.

Achieving a clear understanding of the child's disability can be difficult. A report of children with cancer found that families often had serious misunderstandings of various aspects of their child's condition (Chesler & Barbarin, 1984).

Children with chronic illness. According to Hobbs et al. (1985) parents reported frustration in their search for information both before and after diagnosis. Some physicians remained tentative in their prognoses, often for good reason. The physician who could have given the answers, usually a specialist, was too often unavailable to the parents. When useful information was available, it may have been given in a confusing fashion or at a time when the parents were unable to assimilate it.

Parents varied in their ability to search for information, formulate questions, express their worries, and ask to have information repeated.

If the diagnosis is not made at birth, a common pattern of physician contacts is that a family physician makes a tentative diagnosis and then refers to a specialist for confirmation. If the family is in an urban area with a tertiary care medical center, the child is apt to receive most of his/her care from a specialist there. If such a hospital is not nearby, the child's care usually is split between distant specialists and the local physician. Primary responsibility is often not settled formally. Continuity of care is not the norm (Pless & Perrin, 1985, p. 48).

Children who are ventilator-assisted. For parents of infants who require respiratory assistance, the birth of the baby, the diagnosis, and the decision to ventilate all happen together, as a single, if sometimes prolonged, crisis.

For parents of youths with a progressive disease, such as Duchenne muscular dystrophy, a decision to ventilate is made many years after diagnosis. The progression of the disease is predictable; the average life expectancy is 18.5 years and the most common cause of death is respiratory failure. Ventilator assistance is generally indicated between 12 and 25 years of age, at the onset of respiratory failure, which develops suddenly but may continue for several weeks. In a study of the effects of ventilator use on youths with Duchenne muscular dystrophy, both the youths and their families felt they had made a crisis decision to ventilate (Miller et al., 1988). Most of the respondents said they would have been helped by being prepared for the decision. The absence of education and counseling around this difficult decision may have been attributable to the lack of consensus among professionals on whether or not life should be extended for people with progressive disease (Miller et al., 1988).

Another area of information needed by parents is how to negotiate the health care system. Each family learns from experience, although parent support group members can be helpful (P. Walker, 1988b). A professional case manager would be useful, but if assigned at all, they are rarely available until the child is ready to be released from the hospital, which is usually many months after the child's hospitalization and diagnosis (Aday et al., 1988).

Discharge planning

The decision to bring the child home can be initiated by the parents or by medical professionals. Some parents are determined to do this, despite

poor medical prognoses. Some parents believe that the only chance their child has of surviving requires discharging the child from the hospital. Other parents believe that caring for their child is simply their responsibility, whatever it entails (P. Walker, 1988b).

Given the complexity of medical care for these children, planning, and preparation is important for a successful discharge. This has not been available to all parents. Some parents report having taken their children home with no training at all. Usually the staff of the hospital's intensive care unit provides the medical care training. If there is no formal home care program available, any additional financial, educational, and other support usually comes from the hospital social worker. Rarely is ongoing assistance available after the child is discharged. Coordination of services typically is not provided (P. Walker, 1988b).

Children who are ventilator-assisted. As mentioned earlier, parents in the Aday et al. study (1988) reported a variety of problems and concerns during their child's intitial hospitalization. Most (80%) of the families received assistance for some of these problems, usually from hospital personnel. Emotional support was the help most often mentioned by the caregiver. When asked what other help would have been useful, one-third of the parents reported that it was contact with other parents with children who were ventilator-assisted.

The families in the Aday et al. (1988) study were recipients of three different model programs to prepare and assist them in bringing home and caring for their child who was technology-supported. Probably as a result, two-thirds to three-fourths of the families felt technically well-prepared (because of training and observation in the hospital) to care for their child at home. Yet 7% of the families reported that no professionals (hospital, physician, or home care program) were involved in the planning for discharge. This is an example of feast or famine because the other 93% of families reported an average of six professionals involved in discharge planning.

Guidelines for a comprehensive discharge plan for children with chronic illness are available (American Academy of Pediatrics, 1984). The families in the Aday study reported that an average of 63% of the 15 elements of this plan were included in their child's plans. Most families reported that the doctor listed certain conditions that must be met before the child could be discharged, that plans were discussed for emergencies, that two-family caregivers received training prior to discharge, and that vendor services were available. However, fewer than half the families reported arrangements for social-psychological support or for service maintenance contracts with equipment vendors. The families, overall, were 'somewhat satisfied' with the discharge planning procedures.

About half of the families were assigned a professional (more likely a nurse than a physician) as case manager. About one-third of the other families had a family member designated as case manager. Case management would seem to be a critical service needed by these families (Kirkhart, Steele, Pomeroy, Anguzza, French, & Gates, 1988). One-third of the families felt their best preparation for home care was their belief that home care was best for their child and that they had the personal strength to accomplish it.

Parenteral nutrition. The parents of infants receiving total parenteral nutrition in the UCLA program also received training before discharge. An early step was the joint decision by physician and parents of whether to pursue home care. Families were fully informed of the potential risks, complications, and expected benefits and costs (Cannon, 1980). The adequacy of the home environment was determined. Parents were taught how to set up infusions and how to avoid and to recognize complications such as catheter contamination and reactive hypoglycemia (sudden onset of symptoms caused by low blood sugar). Before discharge, the family caretakers were evaluated by professionals for their performance and understanding of the process (Ralston et al., 1984; Mughal & Irving, 1986). The UCLA longitudinal studies did not focus on the families' experiences with home care, so there is little additional information. Children receiving parenteral nutrition tended not to have home nursing care.

Intravenous drug therapy. As mentioned earlier there was a home care program for infusion of methotrexate (a chemotherapeutic agent) in children with acute lymphoblastic leukemia (ALL) participating in a cooperative group study through The Children's Hospital of Philadelphia. These children received intermittent (every six weeks) 24-hour infusions of methotrexate and were compared with the standard weekly oral methotrexate therapy in children with ALL who have a projected 50% to 75% long-term survival probability (Lange et al., 1988). The progam required a multidisciplinary team to oversee the process, a statement of patient eligibility criteria, and specification of parent training procedures.

The advantages to home infusions of chemotherapy were that: medications could be given according to schedule (rather than being subject to delays in admission into the hospital, and delays in administering the drug); families' lives were more predictable and under more personal control; children were not exposed to hospital infections; fewer physicians and assistants were involved with the patient; parents expressed enormous satisfaction.

Potential disadvantages were that some children could come to require indwelling central venous catheters; children were removed from the psychosocial support provided by hospital personnel and other families; insurance providers could come to mandate home care, which may not be appropriate in some situations; the shift to home care could threaten the financial survival of the pediatric inpatient service; quality assurance can be endangered; it could be a difficult undertaking for children who lived long distances from the hospital in that a local visiting nurse agency is necessary and such agencies tend to suffer from a high rate of turnover, hindering continuity of care (Lange et al., 1988).

Model Home Care Programs

Children who are ventilator-assisted

Three programs had the advantage of having been recently evaluated (Aday et al., 1988). These programs were funded as SPRANS (Special Projects of Regional and National Significance) programs, supported by the Division of Maternal and Child Health. The process consisted of evaluations of planning, implementation, and impact stages. Unfortunately, there were no control or comparison groups nor were pre-intervention and post-intervention comparisons possible.

The original goals for the programs were to develop and implement a regionalized system of care for children who are ventilator-assisted; develop and implement a comprehensive, coordinated model of home care for these children; and improve the well-being of the children and caregivers and to reduce costs.

Program A (in state A) had two separate phases (and staff and locations). Phase I staff focused on developing and implementing a model for discharge planning for children who are ventilator-assisted, but had difficulty getting these plans accepted. Phase II staff focused on developing models for home care for the children, once discharged. During Phase II the program staff were basically absorbed into the Crippled Children's Services home care program, and by the end of the grant period the SPRANS grant principally served to "augment" home care services for children who are ventilator-assisted already being provided through the state's CCS agency. Phase I staff developed guidelines for parents and hospital discharge planners on how to contact the local school district and what could be expected from them. Unsuccessful attempts were made to involve educators in the discharge planning prior to discharge.

Key informants within Program A felt they had succeeded best in developing formal guidelines for discharge and followup, while they were least successful in developing linkages with other institutions or organizations in the states serving children who are ventilator-assisted. Some respondents outside the agency were unhappy with the change in the program from direct service to research and development of home care models. Little community resource development was accomplished. Informants outside the agency believed there was little support in the environment for development of a regionalized system of care. This program experienced very high staff turnover.

Program B. The purpose was to develop a comprehensive, humane, cost-effective system of care and services for individuals who were ventilator-dependent. The program developed out of a discharge program already underway for children who were ventilator-assisted.

Of particular interest was the role of the educational consultant, which was to orient and sensitize special education state representatives and regional coordinators as well as teachers to the needs of the child who is ventilated and to develop education and training materials to explain what they might expect with the child in the classroom. She also developed the protocol for hospital liaison with educational programs during discharge planning. The school training packet was used throughout the state to prepare school personnel for facilitating the child's appropriate educational placement. Many of the instructional protocols developed for the caregivers in the community were included in the training of a child-specific aide in the school system.

The program made development of resources a primary objective. Although unable to get a Medicaid model waiver for their children who were ventilator-assisted, arrangements were negotiated through Medicaid to provide case management services for the children once home. The program survived past the period of the SPRANS grant.

Key informants within the program and outside the program reported they did well in developing linkages with key organizations and increasing the numbers of resources available to children who are ventilator-assisted in the community. Staff itself was a strong aspect of the program. A great deal of time was devoted to location of consistent sources of alternative placement, but they were able to place only one adolescent in a boarding type school.

Program C. The proposal was written by a consortium of organizations and institutions concerned with children who were ventilator-assisted or who had other respiratory disabilities. Key informants inside and outside the program felt the strongest aspects of the program were their

interorganizational linkages and their community resources. Their discharge and home care followup guidelines were also important accomplishments. There was a perception of increased support from all sectors except educators. Their committed staff was also a strong point. Over time there was increasing dissatisfaction with the home care agencies that provided nursing services. At the time of the evaluation, there was need to locate sources of funding to continue the program beyond the grant.

Family satisfaction with home care program

About two-thirds of the families reported they had been involved with a program. Site A had the lowest involvement since it lacked an emphasis on direct care. Site B reported that 79% of the families were actively involved in the program, and Site C reported that 63% were actively involved. Over the three states, 48% of the families felt positive or very positive about their involvement in the home care program, but 12% were dissatisfied and 40% had neutral or mixed responses (Aday et al., 1988).

Summary

These programs served the important functions of assisting families and hospital staff in the transition to home care, informing and coordinating the work of other agencies, providing necessary training and education to involved agencies, and highlighting the many problems facing families as they undertake home care.

Home Nursing Care

An important variable in families' experiences with home care was the amount of nursing care the child with technology-support received.

Children who are ventilator-assisted

In the three-state study (Aday, 1988), there was wide variability in the amount of home nursing care. About 90% of families in two of the states reported daily nursing care, for an average of 12 and 18 hours. By contrast, only 67% of the families in the third state reported any nursing care during the past year, and rarely did these families receive more than eight hours per day (the average was three hours per day).

It was not just nursing services these latter families did without. Seventeen percent of the families in this state reported no professional services during the past year (not even a physician). This variation in

services across the three states was only partly a function of the child's condition. More often it appeared to be caused by differences in the comprehensiveness of insurance coverage and by the availability of professional services.

Variability appears to be the norm. In the Massachusetts study of six children with ventilator assistance, the families ranged from one or two shifts per day of registered nurse care to one or two shifts per week to none (Burr et al., 1983). Ten of the 16 families in the Goldberg et al. study in Illinois (1984) reported three shifts per day of nursing care, another five families had two shifts, and one family received none. Among the five families in upstate New York in the P. Walker (1988b) study, one received 24-hour-a-day nursing care, one had 24-hours-a-day during the week and less on weekends, two families had 16-hours-a-day, and one had no nursing care at all.

The 'Mixed Blessing'

The Aday et al. data showed that families with 32 hours or more of nursing care each week were more likely to feel unprepared for the loss of privacy, while families receiving less than 32 hours a week of nursing care were more likely to feel the weight of the constancy of child care and have feelings of abandonment and isolation (Aday & Wegener, 1988). In the state where nursing care was least available, and in response to the question, 'what help would be useful' almost a quarter of the families reported the need for respite; a quarter, the need for case management; and a quarter, the need for the assistance of specific professionals.

In one of the two states where nursing care was generally used, about 25% of the caregivers were unprepared for 'the loss of privacy', and in both states, 20% were unprepared for the problems of nurse unavailability and scheduling.

The families with nursing assistance in the upstate New York study experienced enormous turnover. One family trained 45 nurses during a 30-month period; and during one week there were 17 different nurses in the home. Parents reported a wide range of competency and dependability. There were nurses who were very uncomfortable about having the parent absent and parents who were uncomfortable about leaving even for short periods. Loss of privacy was reported by the families. It was also common to have communication problems with the nursing agencies (P. Walker, 1988b).

Families in the Massachusetts study also mentioned the loss of privacy as one of the effects of home care (Burr et al., 1983).

In the Frates et al. (1985) retrospective study of children who were ventilator-assisted, only two children (4%) were discharged to nursing homes, the rest were discharged to their families. Almost three-fourths (36) of the families cared for their children by themselves with only occasional outside nursing assistance. Another eight families received part-time care by nursing aides or trained attendants. Of the eight children who received full-time nursing care, seven were younger than five years. This study did not address the families' experiences with and without home nursing care.

Summary

Home care nursing clearly has been a mixed blessing for many families. Families give up privacy, take on administrative and training functions, and sometimes wrestle for control in child care decisions. In return, they are not always assured of consistent, competent care. Staff turnover is a serious concern. Some mothers felt they could not leave their child alone with a nurse. Some anecdotal data describe families who have bypassed home nursing agencies and hired and scheduled per diem nurses on their own. On the other hand, care for many of these children, especially the younger ones, is very demanding. Round-the-clock responsibility, with no opportunity for respite, can be exhausting. The general absence of respite care other than through home nursing services compounds the problems.

Model Day Care Facility for Children who are Technology-Supported

There is certainly a place for alternatives to full-time home care. The private, nonprofit Family Health and Habilitative Services, Inc., in Florida was awarded a SPRANS grant to develop national model standards for Prescribed Pediatric Extended Care (PPEC) facilities and to set up a prototype center (Pierce, Freedman, & Reiss, 1987). The model provided a triad of services by the center: day medical care; developmental programming for the child by trained staff; and parent training.

The model standards address: comprehensive guidelines for a family-centered approach to the child's medical and developmental care; staff experience and credential requirements; physical specifications for the facility; emergency procedures; quality assurance committees to develop, review and revise medical and developmental therapeutic plans; staff training; and advisory board guidelines. These standards serve to encourage reimbursement by public and private insurers.

The PPEC Center was specifically designed as a health care alternative that could be supported by traditional third-party reimbursement mechanisms. Charges are based on hourly rates determined by the intensity of nursing interventions required by the child's medical condition and therapeutic regimen. The authors report that the range of charges for a child placed for 12 hours a day, 5 days a week, is from $600 to $1100 per week or approximately 20% of the cost in an acute care setting and 66% of the cost of in-home skilled nursing care. No other evaluative data have been reported.

Barriers to Home Care

Currently, the most exhaustive listing of the problems faced by families of children who are technology-supported has been provided by the Task Force on Technology-dependent Children (U.S. Department of Health and Human Services, 1988). The purposes of the Task Force were to identify barriers that prevent the provision of appropriate care in a home or community setting for children who are technology-supported and to recommend changes in the provision and financing of health care in order to provide home and community-based alternatives to institutionalization.

The Task Force reported an array of barriers in the medical world. It found no consistent mechanism to support parents in decision-making with physicians and other health care professionals. Parents reported difficulty in getting complete pertinent information about their child's diagnosis and predicted outcomes of treatment. Professionals often lacked knowledge and experience in working in a collaborative process with parents.

There was generally no organized system to assure coordination and monitoring of all needed services and funding sources once the child was in the home. Family training programs for planning and providing appropriate care was unavailable for some. There was no coordination and communication among state agencies, schools, medical, and other service providers. Parents often lacked up-to-date practical information on community services.

Regarding home care, the Task Force noted a lack of nationally recognized and implemented minimal safety and performance standards for care at home. There was a lack of accountability for quality of care provided in the home, and a lack of nationally recognized and implemented minimal safety and performance standards for equipment used in the homes.

Many communities lacked primary medical care physicians, especially in rural areas. This was at least in part attributable to the serious

disincentives for physicians to take on care of children who are technology-supported. These included concern for medical liability, lack of appropriate training, and lack of acceptance of the concept of home care for these children.

There was also a shortage of nurses again, especially in rural areas. The Task Force learned that when nurses were available, parents often had to educate them. Nursing care is usually the most costly component of home care. Testimony before the Task Force (1988) overwhelmingly supported the use of non-licensed professionals and non-professional personnel trained for the care of a specific child.

Family support systems were lacking both in institutions and at home; psychosocial counseling, support groups, and networking for families were rarely available.

The Task Force reported the need for: a systematic approach to caregiver training; access to formal services such as counseling; parent-to-parent support groups; and parent networking (which could include sibling support programs, family resource libraries, and the sponsoring of cooperative purchases of equipment and supplies).

Although respite care was of critical importance to many families, it was often unavailable either in-home (which most families preferred) or in other locations. While some states had appropriated funds to develop respite care programs, that funding was often unstable. Parents were not always aware of existing respite programs. The absence of funding by third-party payers severely limited families' utilization of the services. A generally-accepted definiton of respite care is needed.

Information on community services and sources of financial support was not readily accessible to families and dissemination of information was fragmented. There was too often a lack of awareness on the part of health officials of the difficulties experienced by families and children who are technology-supported (U.S. Department of Health & Human Services, 1988).

Educational System and Families

A major purpose of home care for children who are technology-supported is to allow them to develop under normal circumstances. Obtaining an education is a major task of childhood. An unknown number of families are currently encountering barriers as they attempt to place their children in an appropriate educational environment.

Placement and provision of related services

The Education of the Handicapped Act (EHA) establishes federal-state programs designed to ensure that children with disabilities will have a free appropriate public education. A useful discussion of the educational options for pediatric home care clients is provided by D. Walker (1988). State mandates, regulations, and state and local educational agencies' implementation of the mandates affect a particular child's actual educational program.

Depending on their physical condition, children with normal cognitive functioning and a chronic illness are usually categorized as having an orthopedic impairment, multiple disability, or an 'other health impairment.' Any one of these categorization makes the child eligible for special education and related services.

In many areas, to obtain the 'other health impaired' categorization the health problem must be severe enough to adversely affect the child's school performance; that is, a functioning or severity test is applied. But federal regulations provide neither definition nor advice on the functioning level that makes a child eligible for special education services. Consequently, there are variations in the definitions used by state and local education agencies. In many states a physician is required to determine the extent to which the child's condition interferes with learning.

A child in special education is eligible for: transportation; services of speech, audiology, psychology, physical therapy, occupational therapy, and recreation professionals; early identification and assessment services; medical services for diagnostic evaluations; school health services; social work services in schools; and parent counseling and training. Provision of these related services is controversial in some state and local education agencies because of the costs and of concerns about the appropriateness

and liability of schools providing them. Unfortunately for some parents, this is the only entitlement they have to many of these services.

An example is provided by a brief report on the barriers to school attendance for a nine-year-old girl with multiple disabilities. Melissa Detsel uses a ventilator and a gastrostomy tube for feeding and medication; she also needs periodic suctioning of a trachestomy and continuous monitoring. She receives 24-hour nursing care, paid for by Medicaid. Because a Medicaid regulation stipulated that "private duty nursing services" could be provided in the recipient's own home or in a hospital or skilled nursing facility, she was denied the opportunity to go to school or elsewhere in the community with her nurse. The school system admitted her to classroom-based instruction and provided the necessary health care services; however, there is a court case to determine whether Medicaid or the school is financially liable for the expense (P. Walker, 1988c).

Most school systems are handling children with special health care needs in one of three ways (D. Walker, 1988). First, the children are deemed eligible for special education and related services and their educational placement and the services they will receive are spelled out in their Individual Education Plans (IEPs). Second, they are considered not eligible for special education but receive essentially the same related services under Section 504 of the 1974 Rehabilitation Act. For children who need only related services and not placement in a special class setting, this can work well. Third, the child receives only the existing school health and other services available to children not eligible for special education.

Children served under the Education for the Handicapped Act are entitled to education in the "least restrictive environment" or with their peers without disabilities as much as is feasible. A range of levels of integration should be available from full-time in a regular classroom, to part-time regular classroom with supplementary instructional services, to part-time special class, to full-time special class, to special station, to homebound, to instruction in hospital, special day school, or institutional settings (D. Walker, 1986).

There is wide variability in the placements of children with chronic illness across the nation and within states (OSERS, DOE, 1982). There have been no evaluations on the efficacy of various placements on children with chronic illnesses.

There are few data on the experiences of these children in education programs. Both qualitative and quantitative information would be tremendously useful.

Children who are ventilator-assisted

Early stimulation and preschool programs are becoming more common, especially with the passage of P.L. 99-457, which authorizes services for children, 0 to 3 years of age, who have a disability or one at risk of having a disability. One of the three states in the Aday et al. study (1988) had such a state mandate, but from the numbers available, it appears that, at the time of the survey, the mandate did not provide home stimulation programs to a greater proportion of infants and toddlers than were served in the other two states. The reasons for this are not clear.

Of the children of school age in the Aday study (1988), every child was enrolled in some education program, and no parent reported that the child's physician had advised against enrollment. In this sample, school-age children were in a regular classroom, a special education classroom, or with a tutor at home.

In one of the states, the educational consultant for the model program experienced difficulty getting older children covered under the EHA because many school districts believed that ventilator dependency did not interfere with the child's learning capacity. This became a particular problem if the child needed occupational or physical therapy services. In some cases the educational consultant acted as a lobbyist and advocate. In another of the states, the program filed a lawsuit against a school board to require that a child who is ventilator assisted be enrolled with the necessary support systems. One of the programs trained child-specific aides to care for the child while he/she was in school; the purpose was to eliminate the need for a more expensive person such as an RN or LPN (Aday et al., 1988).

School enrollment of the children with ventilator assistance in the Texas study apparently varied by the age-cohort of the child. The authors stated that many of the children recently discharged from a hospital attended school regularly, since regulations required the state to provide education. Of the 35 children of school age, ten (28%) attended regular schools and eight (23%) attended special schools. Most of the rest received education at home. A few older students had graduated from college and some had obtained professional degrees (Frates et al., 1985).

A report from the Children's Hospital at Stanford University on four of six children with respiratory impairments who successfully used cuirass ventilation noted that three of the youths were attending college. Two were in wheelchairs and one was ambulatory (O'Leary et al., 1979).

Relatively little is documented about the experiences of these children in school settings, but since this is where they will gain and practice many of their social skills, as well as cognitive skills, this is an area needing research.

Children with physical/multiple disabilities

The Palfry et al. study (1989) found that 60% of the parents of these children attended the most recent IEP meeting. By comparison, about 50% of the parents of the less severely handicapped children attended the IEP meeting. Maternal education was a good predictor of IEP attendance and also of placement of the child in a more regularized setting. (Across all disability categories, non-white, non-two parent, non-high school graduate parents were least likely to attend their child's IEP.) The parent's attendance at the IEP meeting was positively correlated with provision of more related services for the children with more severe disabilities.

Absenteeism

Absenteeism is an important factor in a child's school experiences. Children who are technology-supported are at risk for recurrent illness and rehospitalization and need frequent doctor visits. Acute illness and rehospitalizations seriously interfere with schooling and account, at least in part, for below average school performance data. Although the literature contains instances of children overcoming negative school experiences by devoting themselves to study and to intellectualizing themselves, this is a course not open to many (Kleinberg, 1982).

Children with cancer

In a study of absenteeism among 239 children treated for cancer in two states, school attendance records were obtained for five consecutive years (where possible), starting one year before diagnosis. The children (2-18 years at diagnosis) had a high rate of absenteeism throughout, but it

was highest during the first year after diagnosis (mean of 43 days). Even after three years, the rate was higher than for other children (Lansky, Cairns, & Zwartjes, 1983).

Children with chronic illness

A study mentioned earlier of children with chronic illness found that one-fourth of their sample had missed at least six weeks of schooling per year (Sultz et al., 1972).

Recurrent absences mean that children with chronic illness or special health care needs are almost certain to require homebound or hospital classes. Many states require a two-week period of absence before the homebound instruction can begin. In many states these must be consecutive days of absence so that many short absences--which are characteristic for this population--do not accumulate to fulfill this requirement. Nationally, less than two percent of all children in special education placements are reported to be in hospital or homebound placements (D. Walker, 1988).

Barriers to Integration

The Task Force (U.S. Dept. HHS, 1988) reported that school systems were reluctant to admit children who are technology-supported because of unresolved conflict regarding the appropriateness of teachers providing health care services and an unwillingness of school administrators and teachers to assume responsibility for care. There has been little incentive for school personnel and health care providers to develop Individual Care Plans. Walker (1987) found that few states had guidelines for nursing procedures in school (such as, catheterization, seizure management).

Once admitted and with medical/health care issues resolved, children with technology support face the range of potential problems common to children with chronic illness in school. The children reportedly are at risk for developing many school-related problems in both learning and psychosocial domains (Walker, 1987).

Summary

As more children who are technology-supported and in home care reach elementary school, the issues of education in the least restrictive environment and of the provision of related services face more school districts. The small number of these children allows state and local education agencies to treat each child as an exception. Only the largest school districts are likely to have more than a few such children. The differing needs of these children create difficulties in setting policy. The absence of guidance at state and federal levels too often puts parents and local education agencies in adversarial relationships. Few data exist on instances of successful cooperation among parents, health agencies, and local education agencies to meet the needs of these children.

Currently, information on actual school placements of children who are technology-supported is available from only a few states.

Family Experiences with Insurance/Financing

Financial problems

Children who are ventilator-assisted. In the Aday study (1988), almost 40% of the families reported that money was a serious problem with the child at home. Families mentioned foregoing luxuries, postponing the building up of savings, and accumulating debts.

Families who reported that financial issues were a serious concern were specific about their out-of-pocket expenses. Most often mentioned were the increased utility and telephone, supply and medication, and transportation costs.

The family impact scale in the Aday study, provides additional information on the effects of public insurance on stress. Although separate data were not provided, the financial support subscale (e.g., 'additional income is needed to cover medical expenses') found that families with eligibility to obtain funds for home-based care reported that finances were not impacting on the family, while families without the waiver of coverage strongly agreed that there was a negative financial impact. In the state where there was the least insurance coverage, the families were more likely to 'agree' than were families in the other two states. However, when these two sets of families were combined, the average score indicated that

families were only slightly more likely to agree than disagree that there was a financial impact.

Children with chronic illness. In her qualitative research on five families with children with chronic illness, P. Walker (1988b) reported that one single parent who had owned her own business and been self-supporting was reduced to total dependence on public assistance. Other parents reported being behind on paying bills. Another mother expressed the desire to return to work, but was prevented by the absence of stable nursing care.

Financing of home care for these families came from Medicaid and private insurance and occasionally some state and county funds. Parents reported that dealing with the bureaucracies of Medicaid and Supplemental Security Income (SSI) was enormously frustrating. Persuading the authorities that one's child was disabled was the first problem and income qualification was often the second. Medicaid's restrictions on services and supplies sometimes seemed nonsensical (P. Walker, 1988b).

Cost effectiveness of home care

Important as cost-effectiveness data are for policy decisions at several levels of the government and to private insurance companies, there is no single, well-accepted methodology by which comparisons can be made. The Aday et al. study is the most comprehensive to date; a potential drawback to their computations was a total dependence on parents' memories, book-keeping, and comprehension of the systems with which they dealt.

Children who are ventilator-assisted. The Aday et al. (1988) three-state evaluation team investigated whether or not home care was less expensive than hospital care. These calculations were carefully performed. Over the sample of children in these three states, the average cost of a day in the hospital was $907, but the average cost per day in the home was $490. Of the home care costs, nursing and physician costs accounted for 64% of the total.

If the child had bronchopulmonary dysplasia (a less severe disorder from which the child should get better and for which the child may never even have been ventilated), it was significantly less expensive to care for the child at home. If the illness was other than BPD, the costs of home

care varied precisely with the amount of home nursing used. For non-BPD children whose disabilities were more severe, the only source of savings at home was the substitution of parental nursing for professional nursing. Families used more home nursing if the insurance paid for it.

The Massachusetts study (Burr et al., 1983) also performed a cost analysis and reported financial savings of 50-95% of home care versus hospital care. Home care costs ranged from $1,000 to $75,000 per year, while hospital costs ranged from $150,000 to $400,000 per year. Home care costs were highest the first year and finances were particularly complicated during that time. Cash flow was often a major difficulty, largely because of reimbursement delays of Medicaid and private insurance.

Barriers in the financing of home care

The Task Force (U.S. Dept. HHS, 1988) reported that many of the home care services most needed by children with technology support were not routinely reimbursed by either private health insurance plans or by Medicaid and other public third-party payers. This was in contrast to the relatively generous private and public financing for institutional services.

Most current community-based care is delivered under "exceptions" to normal reimbursement policies and approved only in cases in which the payer is assured of cost savings. These exceptions are administratively cumbersome, variable, and rely on public welfare eligibility criteria not designed to consider a family's expenditures along with its income. Most state Medicaid agencies have done little or nothing to publicize the existence of their Section 2176 waiver programs or other Medicaid options for financing care for disabled children (U.S. Dept. HHS, 1988).

Summary

Families reported feeling at the mercy of private and public insurance agencies. Too few families received sufficient assistance in maneuvering through the many agencies. There are many proposals but little agreement among professionals and policy experts on the specific changes needed. There is general agreement that the present insurance systems work poorly for children with technology support and their families.

Family Relationships with the Community

Child-community

Children with chronic illness. A child with technology support, similar to a child with severe chronic illness, generally has nonnormative experiences with the community. This is especially true when the technology support is due to a congenital or perinatal problem. Healthy children gradually expand their familiar environments by incorporating a friend, some neighbors, school-mates and teachers, etc., but a child who is technology-supported is more likely to experience suddenly the intimate contact of professionals and perhaps other children with health impairments. Then, unless special efforts are made by extended family and community members, the child's social environment is likely to remain limited to family members, other children with health impairments, and a circle of familiar professionals (Hobbs, Perrin, & Ireys,1985, p. 54).

Parent-community

Children who are ventilator-assisted. Parents of the children in the Massachusetts study reported they were able to enjoy only limited social lives (Burr et al., 1983). In the qualitative study of the effects of ventilator use on late-stage Duchenne muscular dystrophy, several parents reported that one of the adverse effects of the ventilator was that friends were uncomfortable being around it (Miller et al., 1988).

In the P. Walker study of five families (1988b), several parents reported that old friends often dropped away, usually because they did not know how to deal with chronic illness. Some families were able to make new friends who accepted the constraints placed on family life by the presence of the child. Some parents joined parent support groups to share information and coping strategies and to vent emotions. One mother, however, was unwilling to attend a support group because she was certain her child's problems would be the worst, and because she would have no patience or sympathy for parents with less severe problems.

Children with cancer. A study was made of the factors that separated families who did and did not participate in a self-help group,

among a set of parents of children with cancer. Parents with a high degree of stress about their child's cancer were more likely to join, as were parents who lived closer to the the sessions (Chesler, Barbarin, & Lebo-Stein, 1984).

Children with physical/multiple disability. In the Palfrey et al. study (1988) 17% of the parents of the children with physical/multiple disabilities reported that their child's disability had an effect of their choice of families friends.

Family support group

SKIP, Sick Kids (need) Involved People, is an advocacy and support group for parents of children with chronic illness, many of them ventilator-assisted. There are local chapters and a national organization based in New York City. An important function is to identify resources for families and to advise on how to access them (P. Walker, 1988a). They have recently produced a new edition of their Families to Families handbook (SKIP, 1988). A section on community integration presents a procedure for determining one's needs; other topics include suggestions for becoming involved in changing systems, helping other families, and recommendations regarding school enrollment.

Child-peer relationships

The data in this area are scattered and sparse.

Children who are ventilator-assisted. The initial data on peer relations from the Aday et al. study (1988) show that the caregivers rated their children lower on the Peers Subscale than on the other scales of functioning. (This scale asked, for instance, 'made friends without difficulty' and 'joined others of own accord.') These data are based on a very small sample because questions were asked only about children older than five years, which included only one-fifth of the sample. Fewer than half were adolescents. Since friendships are such an important aspect of normal childhood and adolescence, more extensive information would be useful.

Late adolescents and young adults who had recently begun to use ventilators because of respiratory failure of Duchenne muscular dystrophy reported decreased recreational activities and increased loneliness. These

youths were unable to participate with their friends in the normal transition of moving away from home upon completion of high school. Several youths reported uncertainties about how to explain the ventilator to their friends. Their social lives were also restricted, especially during the evenings, because of the hours required on the ventilator. As one respondent said, ...'if you wen't social before, you'll never be social now.' Another transition-related stress was a sense of failure at being unable to reach one's full potential, educationally or vocationally (Miller et al., 1988).

Children with cancer. Classmates of 12- to 18-year-old youth with cancer were administered a questionnaire to determine their attitudes and behavior towards peers with cancer. Generally positive attitudes and an interest in a visiting program for hospitalized peers with cancer were found (Hodges, Graham-Pole, & Fing, 1984).

Children who are technology-supported. An example of informal support of a child with technology-support by peers is heartening and provides suggestions for activities in this area. A disability-wise second-grader provided her healthy peers with an instructional videotape about caring for a child with mental retardation who received nutrition through a nasogastric tube. She also provided peers with an opportunity to interact with the child. In a pre-post-test design, her peers reported they had learned how to take care of some of the child's special needs and were comfortable taking care of these needs (K. Turnbull & Bronicki, 1989).

Social isolation is common for children who are technology-supported and their families. Although for some families it is the least of their problems, there is abundant evidence that the absence of ongoing, friendly relationships with one's peers deprives a person of important sources of support. The number and quality of friendships is closely related to a child's sense of self.

Summary

Knowledge of the social aspects of the lives of children with technology-support and their families is sparse. It is clear, however, that the children and families are often lacking in the 'free time' that their healthy peers usually devote to social interactions. If there is a likelihood of health deterioration, the time factor becomes even more important.

Given the importance of social relationships and the little time free for developing and maintaining them, there is room for carefully thought-out, targeted interventions, both formal and informal.

VII. IMPLICATIONS FOR RESEARCH

One purpose of this monograph was to assemble what is known about children who are technology-supported and their families in order to make it more obvious what is not known. Much is unknown; the area is rich with research questions.

Incidence, Prevalence and Biomedical Information

Basic numerical data are needed regarding incidence and prevalence. At present, we do not know how many children belong in the category of technology-supported. The Task Force (1988) noted that both epidemiological and demographic research are needed. Current data on the population of children who are technology-dependent are inadequate, and no mechanisms exist for uniform information collection, exchange, and upkeep. Estimates of costs of care are also unreliable and contribute to the reluctance of third-party payers to expand beyond "exception-based" coverage for care at home. No single reliable statistical database exists on costs of children's health care, even acute hospital care.

The Task Force (1988) also pointed out the need for biomedical research. There is limited knowledge about the long-term effects of technology-dependence on children, particularly respiratory-disabling conditions, spinal cord injuries, and conditions requiring parenteral/enteral nutrition.

Characteristics of the Children

As more families and communities gain responsibility for children who are technology-supported, the need for more systematic and detailed information on their characteristics will become obvious.

Cognitive and Social Development

Cognitive assessments with standardized tests should be performed routinely. Such data are useful for developmental and educational planning. The subset of children who are ventilator-assisted as a result of very low birthweight is a special concern.

The prevalence of Attention Deficit Disorder and any predictors of Attention Deficit Disorder in children who are technology-supported is important information that needs to be gathered.

Experiences of the child who is technology-supported. There is little systematic knowledge about the experiences of these children and the effects these experiences have on development. In potentially important ways these children are experiencing lives different from their peers. An obvious difference is the amount of experience they have with health care professionals and hospital systems. To better support the child and family, it would help to know more about the child's perceptions of being a patient.

Quality time. There is a related area in which children who are technology-supported have nonnormative experiences; this is the sheer amount of adult time devoted to them. Again, little is known on which helpful interventions can be designed.

Relationships within Families with Children Who Are Technology-supported

Family Structure

The finding of the high proportion of two-parent families among the samples of families with technology-supported children warrants explanation . It is possible that the need for two parents is so great that parents simply decline to separate. Little is known, however, about the effects of their decisions.

A different reason for the higher proportion of two-parent families in these reports may be a selection factor. Since the studies reported here were focused on home care of children who were technology-supported, and the program (often hospital-related) set conditions for release to home, it may be that the presence of two parents was an important (perhaps covertly important) factor in the decision. There are no comparative demographic data on large numbers of families who did not bring home their child who was technology-supported.

Finally, the greater stress reported by caregivers who were living in an extended family arrangement in the Aday et al. study (1988) is an interesting finding and worthy of further investigation.

Home care. The indications of isolation and exhaustion of the primary caregiver warrant serious consideration. The time the parent devotes to caring for the child can be a significant proportion of each day. More careful studies of the effects of home nursing care on the child, primary care-giver, and other family members may be helpful in developing useful interventions for the family and child. Evaluation of current intervention programs and evaluations of their effectiveness in alleviating these stresses would be useful.

Siblings. There has been little study of the effects on siblings of children who are technology-supported. There are several types of possible effects: the situational effects on the sibling, the effect of the child with technology support on the sibling, and the sibling's effect on the child.

Effects on child-rearing

As can be seen from this review, relatively little is known about the effects of home-based care on the family and the child. Throughout the stages of child-rearing, families are faced with special challenges. Little is known about the specific adaptations that families make.

Relations Outside the Family

School, the child and the family

Effects of preschool. As the child who is technology-supported reaches 3 and 4 years of age, for age-appropriate development to occur interaction with peers and adults outside the home becomes more important. A common source of this stimulation is a preschool program. Across the three states in the Aday et al. study (1988), one-third to two-thirds of the 3-5 year old children were enrolled in either a regular or a special education preschool program. These data were collected in 1985 and 1986; it is reasonable to expect that, currently, education services for this age of child are more available.

The potential advantages of preschool experience are great; children with and without a disability can become accustomed to each other's characteristics in a small, supportive setting where social development is a primary concern. The child can be eased into classroom expectancies, such as sitting quietly, waiting for attention from an adult, cooperating with other children; depending on the child's earlier experiences, these can be very important lessons.

Social interaction problems that arise can often be resolved more easily because a younger child is less attentive to social cues; teachers and parents can undertake preventive education based on their observations of difficulties the child is experiencing in social situations. Children at this age are becoming attuned to society's values and there is a natural desire among caregivers to protect these children from experiencing the social devaluing of people with disabilities that is common in our country. However, protection is rarely as useful as teaching children to recognize, understand, and handle rejection.

From the parents' perspective, making arrangements for preschool can serve as a trial run for making arrangements for the elementary school education that is to follow. The medical arrangements that must be made are perhaps less likely to become the adversarial relationship that is possible when the public school system bureaucracy is involved. Evidence that the child was successfully educated by a preschool program may be a powerful argument for parents to use with a hesitant school system. The preschool hours also provide the caregiver with some respite.

Important research questions are the degree to which these potential advantages of preschool experience are realized. We know there are positive academic and social effects of preschool on children who are economically disadvantaged (Condry, 1984). Are there positive effects on the children who are technology-supported? Are there accompanying negative effects?

Educational placement. Increasingly, educational systems are facing the challenge of providing services that are appropriate to meet the needs of children who are technology-supported. The Education of the Handicapped Act (EHA) ensures educational services for children with special needs which includes the provision of related services, but arguably it was not intended to address the education of children with specific health-related needs (Walker & Jacobs, 1984). Many school systems have

been reluctant to admit children who are technology-assisted (Task Force, 1988). A major barrier to classroom-based education for these children is a definition of "related services." States continue to have significant leeway regarding the definition and in some cases it is the availability of state funds that determines what services are provided (Walker & Jacobs, 1984).

If the child who is technology-supported does not require special education, there is even less consistency in the provision of related services across school districts and states.

The absence of consistent and supportive guidelines from education agencies, health agencies, and the courts has resulted in a range of educational placements for children who are technology-supported. The bases for the decisions are often not known, although they appear to
vary with geographical location, the degree of coordination of services within a community or state, the availability of competent staff, the attitudes of educational service providers, funding limitations, legal liability issues, and state policy (Task Force, 1988; Walker, D.K., 1987; Walker, P., 1987a).

It is precisely in such an unsettled situation that the role of the family could be critical in determining their child's educational placement. The influence a family has in this area will likely vary with their understanding of the educational system and their child's rights, as well as with their knowledge of services available in the community, their confidence in the school health services, their aspirations for their child, their sense of empowerment and assertiveness, etc. The role of medical personnel in the decision process is also unclear.

Considering all of the potential factors that could affect educational services for this population, there is limited information regarding how placement and service decisions are made (Walker, 1987). It has been noted that a lack of discussion about the process of making educational decisions for children who are technology-supported is a serious deficiency in planning (Palfrey, DiPrete, Walker, Shannon, and Maroney, 1987). This is an important area for research and one the Beach Center is investigating.

School, teacher and school aides. Although the classroom teacher must play an important role in achieving social integration into the classroom of the child who is technology-supported, we know very little about this. We might expect teachers to be totally helpful, but their anxieties about their ability to handle the medical, and maybe even social problems of the child sometimes makes this an unrealistic expectation.

Some children who are technology-supported come to school with a full-time aide. One of the programs in the Aday study (1988) trained aides to accompany a child to school. Nursing care was certainly the focus of the training of these aides; we do not know the extent of social skills training that was provided, although this could certainly be useful. Mothers sometimes fill the aide role. To what extent the presence of an aide is a help or a hindrance to the process of developing peer contacts is an interesting question. A special sensitivity to the child's needs and/or specific training in this area should increase the probability of the aide facilitating relations between the child and his/her peers.

Peer relations. There is relatively little information on the development of peer relations by children who are technology-supported, although peer acceptance is a very important aspect of a child's life. It is well-known that peer acceptance during elementary school years is a good predictor of adolescent adjustment. The little data available on children who are ventilator-assisted, and knowledge of common processes of friendship development are not reassuring.

If the child 'looks different,' this has the potential for problems, especially during elementary school years, when visual information is so important in children's judgmental processes and attitudes. Cognitive and social development during the elementary school years focuses on understanding the normative or prototypical roles of people. It is common during this stage for children to reject a child who does not look 'normal'. During this period, being different from one's peers can be an agonizing experience.

The general area of social isolation appears particularly appropriate for future study. The goal of full integration into society cannot occur if children who are technology-supported, and their families are isolated from their peers and their community.

Conclusion

This literature review reports what is known about children who are technology-supported and their families, and suggests several lines of useful research. What is clear is that much is known about the children; less, about their families; and still less about the interactions of child, family, and community.

The Beach Center is attempting to fill the void in the "interaction" area by conducting research on the process and criteria that families and local educational agencies use in making decisions about the child's school placement. People interested in that research should contact Rud Turnbull, Co-director, Beach Center.

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